

# ‘The Missing Discourse’

## How Does the Family History of Cancer Affect the Care Needs of Palliative Care Patients?

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## **ABSTRACT**

There is increasing scientific understanding and growing public awareness of the influence of genetics on the development of cancer. It is known that up to ten percent of cancers are associated with a genetic predisposition. This study asks 'How does the family history of cancer affect the care needs of palliative care patients?' in this context. This question is addressed using the principles of phenomenology to explore the meaning of a family history of cancer for palliative care patients and nurses. Data was collected through recorded, semi-structured interviews with purposively sampled participants. The information obtained was analyzed using Miles and Huberman's (1994) framework, where data is displayed, reduced, and conclusions drawn. Emergent themes were organized around Van Manen's (1990) schema for existential reflection, which considers the relationship between phenomena and four universal themes: lived-body, lived-relationship, lived-time and lived-space. Findings describe how the physical, social, emotional and cultural dimensions of care are modified when viewed through the genetic lens. Patients' poor understanding of cancer and novice nursing practice (Benner 1984) were barriers to appropriately meeting the needs of this patient group. A new approach to the care of palliative patients with a family history of cancer is proposed.

## **Dedication**

This thesis is dedicated to the participants who freely gave of their time and energy to contribute to this study, at a period of their lives when both time and energy were precious commodities.

Thank You.

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With aching hands and bleeding feet  
We dig and heap, lay stone on stone;  
We bear the burden and the heat  
Of the long day: and wish t'were done:  
Not till the hours of light return  
All we have built do we discern  
(Matthew Arnold)

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# CHAPTER ONE: THROUGH THE GENETIC LENS

*If you want to change the world – take up your pen  
(Martin Luther King 1929-1968)*

## Introduction to the Reasons for the Study

Individuals with a family history of cancer are more likely to have experienced the deaths of other family members from the same disease, develop cancer at a younger age than normal and to develop multiple primary cancers (Claus et al 1990, Ford et al 1998, Butterworth et al 2006). Unfortunately there is a dearth of research literature to guide nurses and other health care professionals about how the family history of cancer affects the care needs of the dying (Kneubel and Hudgings 2002, Lillie 2006).

However, a series of clinical encounters that occurred whilst working as a hospital clinical nurse specialist in palliative care drew attention to the fact that patients were being affected by this new knowledge.

Two scenarios were particularly challenging. The first was a seventy year old woman with advanced metastatic breast cancer who was worried about the implications of her cancer for her daughters. Although she had been told by an oncologist that her illness did not imply an inherited susceptibility, the fact that both she and her mother had died/were dying from breast cancer meant that she required on-going reassurance about the potential ramifications of her disease for her adult daughters and granddaughters until she lost consciousness. The second scenario was the identical twin sister of a young dying woman who asked how long it would be until she too developed cancer and died. She and her sister were part of an ongoing twin study and she was aware that her shared genetic heritage might indicate that she had an increased risk of future disease. These encounters were an indication that the knowledge that cancer could be associated with an inherited genetic predisposition was affecting the way some

people perceived the cancer within their family. Reflection on these encounters developed into an interest into the care needs of patients with a family history of cancer.

### Introduction to the Context of the Study

It is now known that up to ten percent of cancers are related to an inherited genetic predisposition to cancer (Claus et al 1991, Collaborative Group on Hormonal Factors in Breast Cancer 2001, Risch 2001). New technological breakthroughs that were developed alongside the Human Genome Project mean that it is increasingly practical to identify the inherited genetic alterations that are associated with adult onset diseases like cancer (Bell 2004). Unfortunately the ability to identify the genetic alterations, which predispose individuals to cancer, has developed more rapidly than the ability to develop effective cancer prevention and control strategies (Sadler et al 2004). Hence the present focus of cancer genetic services is on early and more accurate prediction and treatment of disease, which is frequently associated with improved treatment outcomes and lower morbidity rates (de la Chapelle 2004, Bell 2004). It is perhaps because the ultimate goal of human genome research is the development of new treatments and cures for disease that the effects of this knowledge on the dying have been overlooked (Lillie 2006).

A family history of cancer may be due to shared lifestyle, environmental or genetic factors (Collaborative Group on Hormonal Factors in Breast Cancer 2001). That is, a family history of cancer may be associated with an inherited genetic predisposition to cancer but may also be due to other factors. This study was concerned with any patient who had a family history of cancer, irrespective of cause. Hence it was acknowledged from the outset that the study would include (but not be restricted to) concerns about

genetic predisposition to disease: a major focus of interest for this study. As the scenarios described above demonstrate, clinical encounters had suggested that concerns about an inherited genetic predisposition to cancer could be present for people who were unlikely to be at increased risk of cancer as well as for patients who had an identified inherited predisposition to disease. Information about this aspect of the family history of cancer was timely as a key government objective is to ensure that all healthcare professionals are confident and effective when dealing with genetic susceptibility to disease (DH 2003: 7).

### Introduction to the Research

The overarching research question that guided the study was ‘How does a family history of cancer affect the care needs of palliative care patients?’ It was anticipated that an increased understanding of the meaning of a family history of cancer for palliative care patients would provide insight into their care needs. This was achieved using the principles of phenomenology: a research methodology that gathers, describes and reflects on the everyday experiences of a particular phenomenon to consider their essential meaning within a specific context (Todres and Holloway 2006). Individual experiences are the starting point for this phenomenological enquiry. This was apt for research into palliative care, which was based on a methodology of listening to, and analysing, the needs of individual dying patients (Saunders 2001).

Information was collected through recorded, semi-structured interviews with twelve hospice patients and ten nurses. Although the patient experience was the prime focus of the study, it was anticipated that insight into the lived-experience of nurses caring for patients with a family history of cancer would deepen the analytical understanding and explanation as well as help clarify the tension between the particular

needs of individual patients and the universal requirement of palliative care to provide *'the best quality of life for patients and their families'* (NICE 2004, NCPC 2007).

### The Structure of the Thesis

The thesis is presented in eleven chapters. Chapter Two presents the context and rationale for the study. Chapter Three discusses the ethical and philosophical underpinnings of the study whilst Chapter Four describes the 'natural history' (Silverman 2005) of the research process.

Chapters Five to Nine present the phenomenological analysis. Chapter Five introduces the participants. It describes how their bodily experiences of cancer relate to the indicators of an inherited predisposition to disease, and reflects on the effect of cancer throughout the participants' lifecycle. Chapter Six looks at how the patient-participants' family history of cancer affected their relationships within the family. It draws attention to the effect of previous deaths in the family on family communication and coherence. Chapter Seven uses the concept of lived-time to show how the meaning of the family history of cancer changed for participants when the concept of an inherited predisposition to cancer was introduced. Chapter Eight considers the patient-participants' understanding of the aetiology of cancer, whilst Chapter Nine focuses on the nurse-participants' experiences of caring for patients with a family history of cancer and their concerns with regard to caring for patients and families with an inherited predisposition to disease.

The key implications of the research are discussed in Chapter Ten. The relationships that emerged from the study are discussed from two different interpretive perspectives: from 'outwith' and 'within' a genetics paradigm. The chapter shows that the family history of cancer is a missing discourse within the present model of care and

uses the findings from the study and the research literature to present a new approach to care. Chapter Eleven concentrates on the strengths and weaknesses of the research process. The thesis ends with a personal reflection on the research process.

## **CHAPTER TWO: CONTEXT**

*Men are disturbed not by things, but by the views which they take on those things  
(Epictetus 135-55 BC)*

### **Introduction**

This chapter presents the rationale for this study. It documents four changes that made an examination of the care needs of palliative patients with a family history of cancer an important and timely question. These developments were: a) an increased understanding of the biological mechanisms that cause an inherited predisposition to cancer; b) the impact of inherited genetic predisposition to cancer on clinical care; c) the increasing public awareness of multifactorial disease, and d) concern about the way these developments were affecting palliative care.

### **Inherited Predisposition to Cancer**

The first stimulus for this study was new developments in the understanding of the biological mechanisms that lead to an inherited genetic predisposition to cancer within some families. Cancer is now thought to occur through a multi-step process during which the properties of cells gradually change over time as a series of genetic alterations occur to the deoxyribonucleic acid (DNA) within an individual cell. This gradually confers new traits to incipient cancer cells (Nowell 1976, Kleinsmith 2006). To understand the link between genetics and heritable cancer it is important to be aware that there are two fundamentally different ways that alterations to the cell that predispose an individual to cancer can occur (Rieger 2004). These are somatic (or primarily environmental), and germline (or primarily inherited) alterations. Somatic alterations are acquired after conception and occur within individual cells in a body. Germline alterations occur in either the egg or the sperm at/before conception. They are



present in all the cells of a person's body and can be inherited by future generations (Rieger 2004). Hence all cancer can be considered genetic in the sense that all cancer is thought to occur when the genes are damaged and normal cell function is altered, but only a proportion of cancers are associated with an inherited genetic predisposition to disease (Kleinsmith 2006).

The fact that cancer is a multistep process explains why the greatest risk factor for cancer is increasing age: the longer we live the more alterations we accumulate in our genes (Nowell 1976). It has been suggested that families that have an inherited genetic predisposition develop cancer at a younger age than expected because they inherit certain germline alterations that must be acquired somatically in other families (Frank 2004). Somatic alterations can occur spontaneously during the normal processes associated with DNA reproduction and repair or be due to environmental and lifestyle factors: these include smoking, dietary factors, infectious agents and exposure to chemicals or radiation (Kleinsmith 2006). Consequently, a family history of cancer may be due to an inherited genetic predisposition, but shared environmental and lifestyle factors will also significantly impact upon the amount of cancers within families (WCRF/AICR 2007). Although the somatic alterations that occur within the genome are random there are evolutionary pressures that select which altered cells survive: those that divide fastest will eventually dominate over other cells (Ridley 1999).

The presence of an inherited genetic predisposition to cancer only increases the risk that an individual will develop a particular cancer. The frequency with which a known genetic alteration yields the expected trait within a population is known as penetrance. Incomplete penetrance arises when other components of a person's genetic makeup and/or the environment influence whether a particular trait will be expressed (Kleinsmith 2006). The more penetrant a genetic alteration, the more closely a disease

will show familial clustering of cancers and segregation of the disease in a Mendelian manner (MacDonald et al 2004). However, no identified genetic alteration for cancer is truly deterministic and detailed study has shown varying levels of penetrance signifying significant levels of complexity at a genetic level (Bell 2004). Whether an individual subsequently develops cancer will depend upon different gene-gene interactions and/or the interactions that the individual has with the environment (Peto 2002, Easton et al 2007). Hence an individual with an unusually high liability may not be affected if environmental factors are favourable but the converse may also occur in an unfavourable environment (Harper 2004).

Some of the genetic alterations that predispose an individual to cancer have been identified. For instance, two breast cancer susceptibility genes have been identified: BRCA1 (Miki et al 1994) and BRCA2 (Wooster et al 1995). They were identified through investigation of families that showed a near autosomal dominant distribution of breast cancer that commonly occurred at a young age (Wooster et al 1995). Both these genes are also associated with an increased lifetime risk of ovarian cancer (Wooster et al 2005).

Large population based studies suggest that around one in ten breast cancers are associated with a family history of breast cancer (Claus et al 1991, Collaborative Group on Hormonal Factors in Breast Cancer 2001). These studies also indicate that developing cancer at a young age is associated with an increased risk of familial disease, as is the occurrence of multiple primary cancers within individuals and the occurrence of breast cancer in men (Claus et al 1990, Collaborative Group on Hormonal Factors in Breast Cancer 2001). Nevertheless most women with a family history of breast cancer are not members of families with the characteristics of BRCA 1

& 2 (Claus et al 1998). It is thought that identified susceptibility genes account for less than a quarter of the familial risk of breast cancer (Easton et al 2007).

It has been suggested that there might be a third breast cancer gene, but this has not been found despite intensive searching (Peto 2002). Instead it is suggested that families with a family history of cancer, but no known disease causing variant might carry several inherited disease causing variants that each individually influence disease susceptibility in a more subtle or more complex way (Peto 2002, Hodgson et al 2004). That is, that many familial breast cancers are polygenetic in origin. Large scale genome wide association studies have identified at least four plausible causative genes that show strong and consistent evidence of association with breast cancer (Easton et al 2007). Hence the increased risk of disease in a relative of an affected individual may be the result of hereditary factors or the consequence of a shared environment or a combination of the two (Butterworth et al 2006). There are, however, some comparison and twin studies that suggest that most of the shared risk is inherited (Risch 2001, Hemminki and Chen 2004).

The genetic alterations that predispose individuals to some colorectal cancers have also been identified. These include familial adenomatous polyposis (FAP), and hereditary non-polyposis colorectal cancer (HNPCC). However these two highly penetrant genetic variants probably only account for around five percent of colorectal cancers, whilst different reputable epidemiological studies suggest that many more colorectal cancers are associated with familial disease (De la Chapelle 2004). This suggests that there are other families with a familial linkage that is not fully understood. The explanation for this discrepancy may be associated with polygenetic susceptibility and/or other as yet undiscovered genetic alterations (Lynch et al 2004, Hemminki and Chen 2004). Epidemiological studies suggest that most cancers are familial to

approximately the same degree although there are some exceptions (Risch 2001).

Thyroid, testicular and laryngeal cancers appear to have the most elevated recurrence risk (Risch 2001). There are currently many ongoing studies looking for the particular genes that predispose to other cancers (Bell 2004).

There has also been an increased awareness that epigenetic factors may provide a new explanation for family patterns of cancer. Epigenetic factors are factors that affect the expression of gene activity without alteration to the genome (Feinberg and Tycko 2004). Hitchens et al (2007) found evidence of epigenetic transgenerational inheritance of disease susceptibility in a family with colorectal cancer. This showed that familial cancers could be the consequence of epigenetic changes in one or more genes (Hitchens et al 2007). This finding has been replicated in other studies (Young 2008). The frequency of this phenomenon is unknown and may be uncommon; nevertheless epigenetic mechanisms provide new insight into the mechanisms of inherited susceptibility to cancer (Lynch et al 2007).

It is hoped that this new knowledge will lead to new clinical treatments (Nippert et al 1999). How it is beginning to affect the clinical care of patients is discussed below.

### **Impact of Inherited Genetic Predisposition to Cancer on Clinical Care**

The second stimulus for this study was the knowledge that information about inherited susceptibility to cancer has begun to impact the clinical care of people with a family history of cancer. The fact that specific cancers had a higher prevalence in certain families has been noted for centuries (Lynch et al 2004). There have long been efforts both to understand why this occurs and to care for such families appropriately. For instance, the St Mark's Hospital registry of families with familial adenomatous

polyposis (FAP) was set up in 1925. However it is only recently that technological improvements have begun to enable molecular genetics to inform clinical practice about the mechanisms of disease (Bell 1998).

The government white paper '*Our Inheritance, Our Future: Realising the Potential of Genetics in the NHS*' (DH 2003) makes a clear commitment to harness the potential of genetics and to ensure that the benefits of genetic medicine are realised throughout the NHS. The anticipated benefits include the improved diagnosis of disease, earlier detection of disease, and the development of new individually tailored drugs and treatments (Feetham & Thomson 2006). Genetic medicine is already associated with more accurate prediction of people who are at increased risk of developing cancer in the future and the early identification of cancer in people who are at high risk of developing cancer (Bell 2004). This is important because it is associated with improved treatment outcomes and lower morbidity rates in cancer (Bell 2004). This is discussed with respect to breast and bowel cancer, two common cancers where predictive genetic testing is readily available for the identification of alterations that predispose individuals to disease.

If the family history of disease is indicative of an inherited susceptibility gene for cancer it is now thought appropriate to test individuals for the BRCA 1 & 2 genes within the NHS so that they can benefit from appropriate health education and prevention measures (DH 2003). This includes access to a regular screening programme with the aim of identifying developing cancer at an early stage. This is associated with an increased survival rate at both five and twenty years (Cancer Research 2007). Prophylactic mastectomy is also offered to women at high risk and has been associated with a reduction of incidence of at least ninety percent (Hartmann et al 1999). Hence the early and more accurate prediction and diagnosis of breast cancer can

both reduce the incidence and decrease mortality in people at high risk of developing breast cancer.

Predictive genetic testing is also available for familial adenomatous polyposis (FAP) and hereditary non-polyposis colorectal cancer (HNPCC). The prognosis for patients with colorectal cancers is heavily dependant on stage at diagnosis: the five year survival rate is over ninety percent for Dukes stage-A cancers but only five percent for Dukes Stage-D (de la Chapelle 2004). Hence regular surveillance of people at risk of the disease leading to early detection can affect disease outcome. As breast cancer is the most common cause of death in women in the United Kingdom and bowel cancer the third most common cancer after lung and breast cancer, these discoveries have the potential to enhance the outcome of disease for a significant number of families.

Regular screening is recommended for individuals at high risk of hereditary breast or bowel cancers as it is associated with reduced mortality and increased longevity (Bell 2004). However regular screening means that individuals have to undergo regular procedures, which may be invasive as well as emotionally stressful (MacDonald et al 2004). Procedures like colonoscopy and mammography have attendant risks as well as potential benefits for individuals so it is important that they are only used with individuals who are likely to benefit from them (Burn 2005). Hence one of the main functions of specialist clinical genetic services is to identify individuals who are at high risk of cancer before it develops, and to ensure that they have access to appropriate screening and preventative procedures (MacDonald et al 2004).

### Assessment of Risk for a Genetic Predisposition to Cancer

Traditionally, the risk that an individual would inherit a genetic condition was evaluated through calculation of the recurrent risk (based on the family history of

disease). This can be calculated when there is certainty about a diagnosis, the mode of inheritance of the condition is understood and the biological relationships between family members are known (Skirton et al 2005). However for a multifactorial disease like cancer the inheritance pattern is not clearly understood, so empirical data is used to estimate who is at risk of developing future disease. This has been used to produce evidence based guidelines to assist healthcare professionals identify who may be at risk of developing future disease in families with a family history of cancer. For instance, the Amsterdam criteria were developed to assess the risk of hereditary non-polyposis colorectal cancer.

Unfortunately there are no internationally agreed methods of calculating the risk of heritability of any one particular cancer (Chung and Rustgi 2003). Hence the clinical criteria for hereditary non-polyposis colorectal cancer include the Amsterdam criteria, Amsterdam II criteria, the Modified Amsterdam criteria and the Bethesda criteria. The original Amsterdam criteria were strict and excluded small families so looser, less specific criteria have since been developed (Chung and Rustgi 2003).

Several factors can make it difficult to assess hereditary risk from familial disease including small family size, reduced penetrance, a low number of individuals of the susceptible gender in sex-limited cancers and inaccurate information about the family history of cancer (Trepanier et al 2004). Ongoing research into the inherited predisposition to cancer can also lead to changing risk criteria (Chung and Rustgi 2003). There is less empirical data about the distribution of cancers in families where cancer is polygenetic in origin and, although familial cancers may occur within families more commonly than statistically expected, it can be very hard to distinguish a specific pattern of inheritance from cancers that occur due to shared environmental factors and 'chance clustering' (Berliner and Fay 2007: 247). Hence broader guidelines, (which are

derived from the above criteria), have been developed for referral to a specialist practitioners, who usually completes the assessment of a family history of cancer to assess the risk of an inherited genetic predisposition (DH 2003). To illustrate this point, both the Amsterdam Criteria and the West Midlands Family Cancer Service guidelines for referral are given in Appendix 1.

The family history of disease is only able to show whether there may be an inherited predisposition to cancer within a family. If an individual family member wishes to know whether they themselves have inherited a predisposition to cancer it is necessary that they have a predictive genetic test. There may, however, be a number of potential genes involved and the specific genetic alteration that predisposes to cancer may differ from family to family. Hence it is necessary to identify the specific gene in an affected family member first. This requires a blood sample from a relative who is known to have cancer to allow the unaffected family members to be tested for the specific genetic alteration that is in their familial bloodline (Skirton and Patch 2002, Sadler et al 2004).

Predictive genetic testing can ensure that family members who have a normal population risk of developing cancer do not undergo the risks of unnecessary screening programmes, whilst family members who have a genetic predisposition to cancer have access to regular surveillance programmes (MacDonald et al 2004). Predictive genetic testing is now possible for some familial cancers, however it is a new and rapidly evolving technology and many tests remain imperfect (Feetham and Thomas 2006). Although tests results can clearly indicate the presence or absence of a known cancer predisposing gene in a particular family, they may also give an inconclusive or indeterminate result. An inconclusive result indicates the presence of an altered gene whose significance is not known, whilst an indeterminate result indicates that no known



cancer predisposing gene has been found in a family (Miller et al 2006). However it is thought that there are many yet to be identified altered genes and gene combinations that may cause a history of cancer (Feetham and Thomas 2006). This, alongside the uncertainty about the penetrance of specific gene alterations, means that genetic testing for cancer can still leave families with ambiguous information about their own risk (Miller et al 2006). Hence, even in cancers where genetic testing is possible the family history of disease remains an important clinical tool for risk assessment of cancer (Skirton et al 2005).

### The Role of the Nurse in a General Setting

One key NHS objective is to ensure that all health care professionals are confident and effective when dealing with genetic diseases (DH 2003: 7). Subsequently, guidelines for all nurses, midwives and health visitors have been produced with the aim of developing core educational competencies that are appropriate for all nurses (Kirk 2005a). These are shown in Table One below (P16). This competence based nurse educational framework contains seven core competency standard statements that are appropriate for every nurse. There have been attempts to disseminate these widely, for instance through a series of articles in the *Nursing Standard* (Gaff 2005, Middleton et al 2005, Haydon 2005, Kirk 2005b, Bradley 2005, Benjamin & Gamet 2005, Skirton & Barnes 2005).

It is, however, unclear how thoroughly these competencies have been integrated into nursing practice. In a literature review of genetics in education and nursing, Burke and Kirk (2006) show that although there is widespread agreement about the relevance of genetics to nursing education and practice there is evidence to suggest that there are widespread deficits in the skills and knowledge base. This is often linked with low

confidence levels in nurses' ability to provide appropriate clinical care (Burke & Kirk 2006). This causes concern because it is anticipated that genetic issues will have an increasingly significant impact on the practice of nurses. There have therefore been calls for more information about genetics issues to be inserted into the curriculum for nurse education and research into the most effective means of educational delivery (Metcalf & Burton 2003, Frazier et al 2004, Burke & Kirk 2006).

**Table 1: Core Competency Standard Statements for Nurses**

<u>Core Competency Standard Statements (Kirk et al 2003)</u>	
I.	Identify clients who might benefit from genetics services and information.
II.	Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language level.
III.	Uphold the rights of all clients to informed decision making and voluntary action.
IV.	Demonstrate a knowledge and understanding of the role of genetics and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice.
V.	Demonstrate a knowledge and understanding of the utility and limitations of ones own genetics experience.
VI.	Recognise the limitations of one's own genetic expertise.
VII.	Obtain and communicate credible, current information about genetics, for self, clients and colleagues.

The first core competency for nurses is to identify people who might benefit from genetic services. However, as discussed above, there are specific evidence based criteria for different cancers indicating who may be at risk of different genetic alterations. Due to the specific knowledge required base and the complexity of risk

assessment for cancer, this is usually completed by specialist practitioners. As up to one in three people develop cancer (Cancer Research 2007) many families show some characteristics of an inherited predisposition to cancer. Consequently non specialists are urged to be aware of four key indicators that an inherited germline alteration may be causing a predisposition to cancer within a family, especially in the absence of specific environmental or lifestyle factors, (Skirton and Patch 2002, Kirk 2004b). These factors, which help identify appropriate patients for specialist referral, are shown in Table Two below.

**Table 2: Indicators of an inherited genetic predisposition to cancer**

- Cancer occurs in the same or related parts of the body in different individuals within a family (especially in the absence of shared risk factors like diet or smoking).
- The same or related cancer occurs in several generations of the same family.
- Individuals within a family are affected by multiple primary cancers.
- Individuals within the family develop cancer at a younger age than is usual

These broad indicators appear to hold across different cancers and may be relevant to identifying families with a genetic predisposition to specific cancers where the predisposing genes have not yet been identified, for cancers where no internationally recognised criteria have been developed, and for families where polygenetic origins of cancer lead to more poorly understood pattern of disease in families (Berliner and Fay 2007). These indicators are also helpful when considering whether it may be appropriate to refer a family to a specialist genetic service for risk assessment. Nevertheless there is little evidence to show whether nurses have the confidence or

competence to know who to refer to specialist services (Burke & Kirk 2006). There is, however, evidence that knowledge of inherited susceptibility to cancer is widespread within the general public as will be seen below.

### **The Public Understanding of Multifactorial Disease**

The third impetus for this study was that it was thought that there was sufficient public awareness of inherited genetic predisposition to cancer such that it might be beginning to alter the way people with a family history of cancer understood and experienced their own disease and its potential repercussions for other family members. There is evidence to suggest that there is widespread awareness of inherited susceptibility to cancer amongst the general British population. For instance, a survey of nine hundred practice nurses found that over half of the respondents had been consulted by patients who were worried about a family history of cancer during a three month period (Bankhead et al 2001). Emslie et al (2003) found that nearly half of the participants in a study of families with heart disease spontaneously mentioned that cancer could be inherited. This may be because cancer genetics, especially stories of families with breast cancer, are frequently reported in the media.

Although there is frequent coverage of cancer genetics in the media the presentation of information is not always nuanced, detailed or accurate (Peterson and Bunton 2002). Media stories focus on new genetic discoveries and frequently portray genetics discoveries as a quest to unlock nature's secrets and to find new cures for disease (Peterson 2001), or as personal interest stories that discuss how particular families are affected by familial disease (Henderson and Kitzinger 1999). However the media rarely highlights the multifactorial nature of diseases like cancer (Peterson and Bunton 2002). If environmental causes are discussed in conjunction with genetics it is

usually only in passing and towards the end of an article. Furthermore, the fact that the aetiology of disease is multifactorial and may be due to the interaction of different genes is rarely mentioned (Peterson and Bunton 2002).

*Clarke (2004) shows how breast cancer in particular is portrayed as a threat to the family in the media. She describes how the family is described as both the source of love and the source of a fearsome disease that paradoxically both threatens and strengthens family ties (Clarke 2004). Cancer is described as a family curse, a legacy and even as a member of the family (Clarke 2004: 545). Media stories have provoked spontaneous conversation in the general public about what preventative and prophylactic treatments they would consider if they were in that situation (Henderson and Kitzinger 1999) and can suggest that the whole family has become diseased (Clarke 2004).*

The language used to describe genetic predisposition to disease also has the ability to influence how individuals and communities perceive genetic conditions (Hodgson et al 2005). Within clinical genetic practice the language used to discuss the genetic diversity is clearly defined. For instance, the term ‘mutation’ is defined as a ‘change in the normal structure or sequence of a gene’ (Young 2005: 295) or as a change in genetic material, either of a single gene, or in the number or structure of the chromosomes (Turnpenny and Ellard 2007). The word ‘polymorphism’ is used to refer to the occurrence in the population of two or more genetically determined forms which occur in such frequencies that the rarest of them could not be maintained by recurrent mutation alone (Turnpenny and Ellard 2007). By convention the term polymorphism is used for gene sequence alterations that are found in more than one percent of the population, whilst the term variant is used for gene sequence alterations that occur in less than one percent of the population (Young 2005).

The word ‘mutation’ is commonly used in both medico-scientific literature (Hodgson et al 2005) and the media (Peterson and Bunton 2002). However this has been shown to have strong negative connotations for people who often associate it with science fiction mutants and ‘scary’ science (Condit et al 2004: 248). It has been shown that the words ‘variation’ or ‘alteration’ have more neutral associations. It is suggested that their use would help ensure that unintended negative meanings are not conveyed when discussing genetic risk and illness (Condit et al 2004). However the word ‘variation’ is easily confused with the clinical term variant (discussed above), so the word alteration has been used throughout this thesis.

It is known that the way people assess their own risk of developing multifactorial disease differ from the medico-scientific method of assessing risk. Walter et al (2004) systematically reviewed and synthesized the qualitative literature that explored the lay understanding of familial risk of common chronic diseases including cancer. They show that familial risk perceptions are affected by the salience of the disease to an individual, how the individual personalised the risk and also their individual sense of vulnerability. Walter & Emery (2005) later interviewed thirty individuals who had a family history of common chronic diseases including cancer. They state that the development of a personal sense of vulnerability depended on both how the biomedical model of counting affected relatives and also on a sophisticated interplay of emotional factors, including the emotional closeness to the affected family members, impact of witnessing illness in the family and the physical similarity to affected relatives.

### The Effect on Society

There are also concerns about the social consequences of the rapidly expanding understanding of human genetics (Cunningham-Burley & Kerr 1999, Conrad & Gabe

1999, ten Have 2001, Cunningham-Burley & Kerr 2002, Bunyon & Peterson 2005).

Many of these focus on practical concerns about the use and misuse of genetic information. This is because genetic information contains a unique identifier of each individual alongside heritable information that has relevance to other family members (Feetham & Thomson 2006). These include concerns about the issues of confidentiality, choice and discrimination.

Concern about discrimination and the social impact of genetics is often associated with the eugenics movement. The eugenics movement is discussed in Appendix Two as the ramifications of eugenics are important and widespread; nevertheless they are peripheral to this study which focuses on care of the dying rather than reproductive decision making. Concerns about discrimination is, however, an important consideration for people living with a genetic predisposition to disease because the knowledge of an inherited trait not only provides information that individuals can use to inform their own lifestyle and health choices, it can also affect the way they are treated by society (Shiloh 1996). Individual life choices, including career and important relationships, can be affected (Finkler 2000). There may be fiduciary implications with, for instance, consequences for life insurance, health insurance and even mortgages (Morgan 1996, Doukas 2003). Knowledge of inherited susceptibility to disease can also have a fundamental affect on families and the way they view themselves (Finkler 2000).

### The Family and Genetic Predisposition to Cancer

Traditionally, in the western world, including Britain, a family was defined as a group of persons linked by kinship, which can be established through lines of descent that connect blood relatives or through marriage (Kissane & Bloch 2002). However this

definition of a family has been challenged by many social changes including high rates of divorce, increasing incidences of lone parenthood, advances in the control of fertility and a liberalisation of attitudes towards homosexual partnerships (Payne et al 1999). This has generated a diversity of new family ties that are subject to negotiation and frequent change (Finkler 2000).

The concept of inherited predisposition to disease can challenge the way families perceive themselves (Finkler 2005). It challenges the fluid social definitions of family and re-inforces older definitions that are grounded in biologically produced ties (Finkler 2005). This is because the risk of inherited illness only exists for biologically related family members, and the information used to define who is and is not at risk of disease is based entirely on the concept of shared DNA. Consequently the knowledge of inherited predisposition to disease can re-establish traditional conceptualisations of a biogenetic family, established through lines of descent that connect blood relatives, and exclude individuals who are defined as family through social choice like adoptees or step children (Finkler 2005).

When confronted with any life-threatening illness each family member has to redefine their expectations of themselves and their relationships with one another. Any illness experiences can challenge families and their sense of cohesion leading to a profound redefinition of the family, who they are and how they relate to one another (Altschuler 2005). There are, however, added dimensions for families who are confronted with genetic illnesses (Richards 1996).

The increased impact of genetic disease on families is so significant that it is claimed that genetic diseases are family diseases and that the patient is the family in clinical genetics (Richards 1996, Peterson 2005). Specific concerns include issues about who may be responsible for introducing the disease into the family and the need



to adjust to the risk that each family member may develop the disease or carry the gene that predisposes to illness into future generations (Richards 1996). Hence the revelation of an inherited predisposition to disease within a family involves an initial period of adjustment for all the individual members as they communicate and learn about whether they or other relatives may be affected (Rollands and Williamson 2006). There is evidence that knowledge of a genetic predisposition to disease can cause a variety of emotions, tensions and recriminations within families (Richards 1996, McAllister et al 2007).

It can be especially difficult for individuals who are aware that they are carriers of a heritable cancer (Wagner-Costalas et al 2003). They can feel guilty and responsible for introducing the gene into the family (Hallowell et al 2006). Parents may feel especially guilty that they may be responsible for transmitting an increased risk to their children (Agincourt-Canning 2006, Hallowell et al 2006). For the affected individual, knowledge of a genetic disorder can promote feelings of isolation, self- stigmatisation and loneliness (Wood-Harper & Harris 1996, Kenan et al 2006). Other family members may feel guilty that they have not inherited the predisposition to disease, separating families psychologically (Madigan 1996).

When an individual is told about inherited susceptibility to cancer they themselves become involved in dilemmas about how, or whether, they should inform relatives of this (Hallowell et al 2003). Communicating within a family can be difficult as different family members may have different attitudes to genetic information (Madigan 1996), and knowing that there is an increased risk in the family can cause distress to relatives who would prefer not to know (Madigan 1996). It may be unclear who should be responsible for telling different individuals within a family (Forrest-Keenan et al 2005, Forrest et al 2003) and even who should be defined as family (Foster et al 2004,

Forrest-Keenan et al 2005). The experience of a genetic predisposition is also unusual because it frequently includes a period of awareness of potential illness before the disease shows clinical symptoms (Rollands and Williams 2006). People who are at risk of developing future disease can find themselves in a liminal position between health and sickness, leading to increased monitoring of health and an increased desire for health surveillance (Scott et al 2004, Finkler 2001). There is, however, little information about how knowledge of inherited susceptibility to cancer affects patients with advancing incurable disease.

### **Impact on Palliative Care**

The fourth impetus for this study was the awareness that concerns about familial disease were impacting on patients receiving palliative care (as described in the introduction). Palliative care is:

*'... the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients' and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. Palliative care aims to*

- *Affirm life and regard dying as a normal process*
- *Provide relief from pain and other distressing symptoms*
- *Integrate the psychological and spiritual aspects of patient care*
- *Offer a support system to help patients live as actively as possible*
- *Offer a support system to help the family cope during the patient's illness and in their own bereavement* (NICE 2004, NCPC 2007).

Palliative care affirms life and regards dying as a normal process. It attempts to offer support systems to help the terminally ill live as actively and creatively as possible until death (Twycross 1995). The word 'palliative' is derived from the Latin word for 'to cloak' or 'to cover' and indicates that the focus of care is on covering the symptoms of progressive disease and death rather than cure (Twycross 1995).

The NHS Cancer Plan (DH 2000) stated that palliative services should be available to all patients dying from cancer. It is estimated that ninety-four percent of patients admitted to inpatient units providing specialist palliative care have cancer and that approximately seventy percent of people who die from cancer within the United Kingdom are seen by a specialist community palliative care team (Hospice Information 2007). As around one in ten cancers are associated with familial disease (Clause et al 1991) it can be suggested that specialist community services may see around ten thousand new patients with a family history of cancer each year, and that there are approximately four thousand patients admitted to hospice annually where familial disease has the potential to be a relevant factor in care.

### The Family in Palliative Care

Care of the family is an integral part of palliative care (WHO 2002, NCPC 2007). The family provides the most important social context within which health is maintained and illness occurs (Bond & Bond 1986). Terminal illness profoundly influences families, not only because of its effect on family activities, roles and relationships, but also because it confronts them with overwhelming issues associated with death and transcendence beyond death (Panke & Ferrell 2005). A systematic review of ninety four papers suggests there is unequivocal research evidence to show that good patient care, good communication and good information giving to patients and families are of decisive importance when supporting families through the dying process (Andershed 2006). A systematic review of the effectiveness of interventions to help families found that they generally prioritised the need for information and psychosocial support (Harding and Higginson 2003). Although the palliative care movement has embraced the desirability of family centred care it has struggled to

devise means of doing this effectively (Kissane & Bloch 2002), and the National Institute for Health and Clinical Excellence (NICE) have highlighted the need for more research into the care needs of families at the end of life (NICE 2004: 358).

The term ‘family’ is often loosely defined in the palliative care literature to include caregivers and those who have strong societal, emotional and care-giving links to the patient (NICE 2004). That is, palliative care often uses a functional (Parsons 1955) definition of family. This is illustrated by Andershed (2006) who drew attention to the different ways that family was conceptualised in the ninety four papers she reviewed. These included ‘caregiver, carers, informal carers, primary caregiver, home caregiver, cancer caregiver, caring relatives, relatives, spouses, next of kin, family caregiver, family carers, family member and family’ (Andershed 2006: 1160). Not one of the ninety-four papers defined family in terms of their bio-genetic linkage. This is a significant omission as only people with bio-genetic ties will potentially be at risk of developing the same or related cancer in the future. This may profoundly affect the way families relate to one another whilst someone is dying (Mallet and Chekroud 2001).

Andershed also comments that patients were considered separately from families and notes the need to integrate the care of patients and families. She states that irrespective of the word used to define family the outcome was the same: ‘one person as a voice for the family’ (Andershed 2006: 1160). However different family members frequently have very different perspectives (Kissane and Bloch 2002), and the perspective of a family member with a shared predisposition to disease might be different to family members without the genetic variant.

Families also typically follow a life cycle: couples commonly move from being childless, to parenting young children, then experiencing those children growing up and leaving home, then perhaps becoming grandparents (Riches & Dawson 2000). Each

change in stage involves families and individuals in emotional processes of transition and major changes in family structure and relationships to allow individual and family development (Rolland 2006). Hence through a family's life cycle the roles of individuals change, as do the relationships between individuals with time (Payne et al 1999). The impact of death within a family is altered by the stage of the family life cycle in which they occur (Riches & Dawson 2000, McDaniel et al 2006). Patients needs are influenced by/and interlinked with the needs of their families and hence by the stage in the family lifecycle in which their illness occurred.

### Genetics and Palliative Care

There has been little research into how the palliative care needs of adults are affected by inherited genetic predisposition to disease (Lillie 2006). Table Three highlights the key literature on this topic which was identified through a review of the literature.

**Table 3: Literature about palliative care and genetic medicine**

Author	Level of Evidence	Aims	Experience/ Perspective	Key Concerns and Arguments
Clifford et al (2007)	Survey of 328 adult hospice nurses	To identify the training needs required by hospice nurses to support patients with genetic conditions	University Researchers (UK)	Nurses had a low level of confidence in dealing with genetic diseases  Need to develop educational provision
Kirk (2004a)	Opinion Paper	To alert/encourage palliative care services to the benefits of genetic testing	Director of a Familial Cancer Service: has been involved in the genetic testing of palliative care patients (Australia)	Raise awareness of indicators of inherited disease Alert readers to the ethical & practical implications of testing at the end of life
Lalloo et al (2000)	Opinion Paper	To highlight the importance of obtaining accurate information about a family history of cancer	Consultant Geneticist (UK)	Palliative care can be the last opportunity to obtain a family history of disease from older relatives Important to assess family history for inherited predisposition to disease
Lillie (2006)	Literature Review	To understand how the awareness of genetic predisposition to cancer was affecting palliative	Palliative Care Nurse and Ph.D. Student (UK)	Need for further research to better understand how to support patients with concerns about genetic predisposition

		care patients		
Mallet & Chekroud (2001)	Opinion Paper	To highlight the risks of emotional distress when discussing inherited disease with the dying	Hospital Physicians (French)	Death is inherently psychologically challenging for families. It is possible to do harm by adding concern about genetic predisposition at this time

Three of these papers (Kirk 2004a, Laloo et al 2000 and Mallet and Chekroud 2001) are opinion papers that discuss the issue of risk assessment at the end-of-life. Expert opinion is frequently systematically biased in favour of performing procedures in which the expert has a vested interest (Mulrow 1995, Shekelle et al 1999).

Fiona Laloo (2000) and Judith Kirk (2004a) are both specialist geneticist practitioners. They emphasise the potential benefits of identifying families at high risk of genetic predisposition to disease within a hospice environment. They point out that palliative care may be the last opportunity for an elderly relative to document the family history of cancer for future generations. This can inform future generations of their family history of disease and inform them about potential susceptibility to disease. It may also be the last chance for a family member who has cancer to undergo genetic testing to identify the specific genetic alteration to which the family may be susceptible. This allows other family members to have predictive genetic testing to learn whether they individually are at increased risk of developing cancer in the future. Blood banking, for testing in the future should relatives decide to consider genetic testing after the family member with cancer has died is also possible. Although Kirk (2004a) draws attention to the ethical issues like gaining consent and the potential for conflict within families involved with predictive testing with terminally ill patients, the assumption that underlies these articles is that the benefits of predictive genetic testing outweighs the potential risks.

Mallet and Chekroud (2001) are physicians, not genetic specialists. They emphasize the potential for discussion about genetic disease to have a negative psychological impact if the topic is introduced when a patient is dying. They suggest it can provoke guilt and recrimination in patients and their families. Their key concern is to highlight the importance of maintaining a patient autonomy, and they suggest that this should take precedence over any potential benefit that testing might have for the family unit as a whole. None of these opinion pieces give details about particular incidents or specific cases to allow the reader to evaluate the evidence upon which their opinions have been formed; but all do highlight the potential for the dying process to be affected by fears about inherited genetic predisposition to disease.

Clifford et al (2007) surveyed three hundred and twenty eight adult hospice nurses to identify nurses training needs to support end-of-life patients with inherited predisposition to disease. They found that adult nurses had low levels of confidence when dealing with the physical, clinical and biological aspects of inherited disease. They draw attention to the need to develop educational provision that integrates the clinical and biological aspects of care. However, this was primarily determined through a Likert scale questionnaire and had limited space for qualitative free text data to ascertain why their level of confidence was low in this area of care.

The short free-text responses were analysed using content analysis (Clifford et al 2007). A fifth of the comments received were made by individuals commenting on their lack of experience caring for families with an identified genetic predisposition. The illnesses that provoked most comment were breast cancer and Huntington's disease, but bowel, bladder, ovary, thyroid and oesophageal cancers alongside familial CJD, cystic fibrosis and Von Hippel-Lindau syndrome were also mentioned, showing that concerns about the family history of disease can affect a wide spectrum of palliative care

patients. The respondents commented on the wide range of emotions provoked within families by genetic testing within a hospice environment including guilt, fear, anxiety and family discord. They also noted the emotional impact that these additional issues had made on them as staff and a fifth commented that they felt such issues should be dealt with prior to palliative care. This shows that palliative care nurses had cared for patients and families with identified genetic alterations which predispose to cancer as well as other inherited illnesses.

Clifford et al (2007) also surveyed children's hospice nurses. They reported higher levels of confidence than their counterparts working in adult hospices. This may be because most children's hospice nurses routinely care for patients and families with commonly recognised genetic conditions (Clifford et al 2007). If this is correct, it suggests that many adult hospice nurses do not think of cancer as a genetic disease. Several respondents commented that they had not realised the importance of genetics to their nursing practice prior to completing the survey (Clifford et al 2007).

Lillie (2006) reviewed the literature that examined the affect of genetic predisposition to cancer on palliative care patients. It showed that there had been very little consideration of how this issue might affect people with advancing terminal disease. Although a comprehensive search strategy was used it is not a systematic literature review. Hence it is possible that relevant research, (especially studies reported in languages other than English), were overlooked.

The review of the literature only found opinion pieces about the needs of palliative care patients and relatives, a survey that suggested that adult hospice nurses were not confident in dealing with biological, psychosocial or clinical aspects of care and a literature review that showed more research was required. Nevertheless these papers did confirm the potential for inherited genetic predisposition to affect care. There was,



however a dearth of literature looking at the patient's perspective, and how the knowledge of genetic predisposition was affecting their experience of palliative care. This was the final stimulus for this study.

## **Conclusion**

This chapter has presented the rationale for a study into the care needs of palliative patients with a family history of cancer. It describes how new knowledge about the biological mechanisms of familial disease are impacting on clinical care. It has shown that the knowledge of genetic predisposition to cancer can affect patients and families but that there has been little research into how this affects patients receiving palliative care.

The next two chapters describe the process of designing a study to consider this issue. Chapter Three discusses the ethical and philosophical issues that defined the scope of the study whilst Chapter Four describes the research process.

## CHAPTER THREE: THE ETHICAL AND PHILOSOPHICAL FOUNDATIONS

*Be careful then, and be gentle about death. For it is hard to die,  
It is difficult to go through the door even when it is open.*  
(D. H. Lawrence: All Souls Day)

### **Introduction**

A prime concern throughout the research process was to ensure that a meaningful and ethical approach to the research was maintained at all times. Consequently this chapter initially discusses the ethical issues that shaped the research process and then presents the rationale for using the Heideggerian hermeneutical phenomenology that was chosen as the research methodology. It documents the importance that was placed on designing a study that enabled the researcher to compassionately and sensitively elicit the experiences of participants, whilst ensuring a reasonable expectation of obtaining meaningful information. This is of the utmost importance when researching in palliative care (Seymour and Clark 1998).

### **Research Ethics**

The first step in designing this study was to think through the ethical issues involved. There are three types of ethical issues that are commonly identified in research with human subjects (de Castro 1998). The first relates to questions of autonomy and respect for research participants and the second pertains to justice in the distribution of benefits and burden of research related activity. The third involves the accurate assessment of potential benefits and risks of harm (de Castro 1998).

To avoid exploitation of participants the research process must allow participants the opportunity to make autonomous decisions based on their own value systems (de Castro 1998). This means ensuring that their participation is both informed and

voluntary. Informed consent occurs when participants are given sufficient information about the proposed research, are capable of understanding that information, and have the power of free choice which allows them to give or withhold consent to participate (Polit & Hungler 1997). Issues of justice include the fair and non-discriminatory recruitment of participants, the non-prejudicial treatment of people who refuse to participate in research and the honouring of agreements made between the researcher and the participant, including respect for confidentiality and anonymity. It also pertains to the appropriate use and dissemination of research results (Polit & Hungler 1997, de Castro 1998). The processes used to ensure appropriate recruitment and informed consent are discussed in Chapter Four.

The theoretical foundation for a risk/benefit evaluation can be found in the principles of beneficence and non-maleficence. Reference is often made to Kant's Categorical Imperative; 'Act in such a way that you treat humanity in both your own person, and in the person of all others, never as a means only but also equally as an end' (de Castro 1998). In non-therapeutic research, like this study, where there were no anticipated direct benefits for participants, the potential risks to participants needed to be considered commensurate with the potential benefits to society. It was therefore incumbent on the researcher to minimise potential risks to participants (Polit & Hungler 1997). There were two key specific issues that needed to be considered before commencing this study. These were the ethics of research with palliative care patients and consideration of the sensitivity inherent in the topic of a family history of cancer.

#### The Ethics of Palliative Care Research.

This study was undertaken in the belief that research into the needs of palliative care patients was a necessary activity to guide practice and inform service development

(Bruera 2000, Jubb 2002, Karim 2005). However it was recognised that participants with advanced incurable cancer constituted a vulnerable participant group (Dean & McClement 2002, Karim 2005). People with terminal illness are considered vulnerable due to their physical decline, which is often associated with debilitating symptoms. Their situation is further complicated by the emotional intensity inherent in the knowledge of impending death and the reality of diminished time (Dean & McClement 2002).

Vulnerability arises in several ways (Regehr et al 2000, Dean & McClement 2002, Karim 2005). Intrinsic vulnerability is associated with factors such as age or reduced cognitive ability. Extrinsic vulnerability is associated with factors like hospitalisation or financial hardship. Relational vulnerability stems from the unequal balance of power, which can occur in interactions between caregivers and patient. Palliative care patients are often vulnerable in all three dimensions (Regehr et al 2000, Dean & McClement 2002, Karim 2005).

Research participants who will not benefit personally from the research are also highlighted as a vulnerable group in the Declaration of Helsinki (2000) and there are specific guidelines for research studies where this applies. This is because ‘in research on man the interests of science and society should never take precedence over considerations related to the well-being of the subject’ (Declaration of Helsinki III: 4). As this includes palliative care patients who are unlikely to live long enough to benefit from the information that this research will provide, the research was designed in accordance with these guidelines that 1) all participants should be volunteers, 2) that the research should be discontinued if it was perceived to be harmful to individual participants and 3) that the prime duty of the practitioner is to protect the life and health

of the participant. The duty of care to patient-participants under the NMC code of conduct was given full consideration during each stage of the research process.

The ethical understanding behind this research reflects a belief that well designed research which has a reasonable prospect of leading to relevant knowledge that may benefit people in the future is appropriate in palliative care, whilst acknowledging that the vulnerability of palliative patients means that particular and compassionate attention must be applied to ethical principles throughout the research process (Rees 2001, Jubb 2002, Dean & McClement 2002, Lee & Kristjanson 2003, Karim 2005).

### The Ethics of Research into the Family History of Cancer

This research was predicated on the assumption that the knowledge that a family history of cancer could be associated with an inherited genetic predisposition could make a difference to the individuals experience and representations of their cancer. Hence it was important to consider the potential ramifications of raising the topic of a family history of cancer. This was to ensure the study was designed in such a way that it minimise any potential risks to participants.

The literature highlighted three different areas of concern:

- The effect of knowing that familial disease is associated with a genetic predisposition to cancer
- The ambiguity associated with genetic predisposition and risk
- Specific issues associated with palliative care

## The effect of knowing that familial disease is associated with an inherited genetic predisposition to cancer

It has been suggested that the lack of research into the effect of being identified as being at risk of an inherited genetic predisposition to cancer on people who have cancer is an oversight on the part of researchers (Hallowell et al 2004). However, Bonadona et al (2002) found that over half of his participants (who all had cancer) reported at least one negative feeling and nearly a third felt distressed after being told that their cancer was due to an inherited genetic alteration. Most were concerned about the implications for their children's health. They may also feel guilty that they have been responsible for transmitting an increased risk to their children (Hallowell et al 2006, Kenan et al 2006, Van Oostrom 2007). Although these results were not replicated in all studies (Hallowell et al 2004) they underscored the potential for discussion about familial cancer to distress research participants.

Although current evidence suggests that adverse psychological consequences of knowledge about inherited predisposition (through genetic testing) are uncommon in people who have not previously had a cancer diagnosis (Broadstock et al 2000), there is evidence that certain individuals may be at increased risk of negative psychological outcomes such as depression, distress and anxiety (Vadaparamphil et al 2004). The documented risk of psychological harm meant that the potential for the study to cause distress if it introduced fears about genetic predisposition had to be taken seriously and emphasised the need to ensure that the research design minimised the potential distress to participants.

### The ambiguity associated with genetic predisposition and risk

The ambiguity associated with genetically inherited risk factors is well documented in the literature (Callahan 1996, Berliner and Fay 2007). Even the results of predictive genetic testing are ambiguous. This is because the discovery of a genetic variant associated with cancer does not lead to the certain knowledge that an individual will develop cancer. Rather it indicates that they have an increased statistical risk of developing cancer at some indeterminate point in the future (Callahan 1996). There is even greater ambiguity involved when using the family history to assess risk (Berliner and Fay 2007).

Unfortunately the limits on genetic information are not well understood. It can be difficult even for healthcare professionals to understand the implications of a statistical risk for an individual (Gigerenzer & Edwards 2003). It is also difficult for patients and relatives to apply these statistics to their own situation (Shelford 2003). This, linked with the tendency to reduce complex phenomena to simpler models, leads to an attitude that can link the knowledge or likelihood, of a genetic alteration that predisposes to cancer to a perception of genetic fatalism: that the family is doomed to cancer. The knowledge that genes operate within particular environments and in the presence of additional causal factors is often lost in the popular discourse (Callahan 1996, Sherwin 2004).

### Specific issues associated with palliative care

It has been suggested that the topic of genetic predisposition to cancer is a particularly sensitive subject within a palliative care setting. This is because it risks disturbing the complexity of the conscious and unconscious ties that constitute the family structure (Mallet & Chekroud 2001). Family ties and interactions are often

particularly intense when a family member is dying. Relatives may be increasingly aware of their own susceptibility to future disease (Sanders et al 2003). It may also lead to an increase in recollections of previous deaths within the family, which may or may not be healthy for the family as a whole (Mallet & Chekroun 2001).

This meant that the research question ‘How does a family history of cancer affect the care needs of palliative care patients?’ had to be considered sensitively, not only because of the obvious risk of bringing to the fore distressing memories associated with previous bereavements, but also because the topic of a family history of disease, with its new, widely publicised, attendant overtones of inherited predisposition to cancer, had the potential to cause new tensions and stress to vulnerable participants. It was therefore decided that it would be inappropriate for the research to introduce the topic of cancer genetics directly into the research study.

#### Reflections on the Impact of Ethical Consideration on this Study

On reflection, the sensitivity of the topic of genetics linked to the vulnerability of the research participants was the single most important factor in the design of this research study. The potential for the study to harm participants was taken seriously throughout the research process.

The design of any research study is a critical aspect of ensuring that a framework for addressing ethical issues is developed (Seymour & Ingleton 1999/2005). In this study many of the key decisions about research methodology were taken to reduce the potential for harm. The decision to proceed with an in-depth exploratory study of how a small number of participants were affected was made primarily because of the ethical issues associated with the research topic, as well as the anticipation that it would provide new insight into a complex and topical issue. Interviews were selected as the



data collection method as it was felt they reduced the potential for the research to provoke emotional distress. However, even using semi-structured qualitative interviews (the data collection method chosen for this study), it was felt that the topic of cancer genetics was too sensitive to openly and systematically raise it with palliative care patients. Even the term ‘family history’ was felt to be too indicative of genetic disease in this context. How this was overcome is documented in Chapter Four. The scope and direction of this study was directly affected by the requirements of ethical research practice from an early stage in the research process.

### **The Philosophical Understanding behind the Research Methodology**

There is no consensus on the best way to study the social world or how to systematically approach the study of human action (Holloway and Wheeler 1996). Hence a variety of different methodologies are currently used as tools to understand human society. However, it is widely agreed that the selection of a research methodology should not be due to personal preference, fashion or whim but rather should reflect a harmony between the aims of the research and the underlying assumptions about the nature of reality as understood by the researcher (Van Manen 1990, Crotty 1998).

This study uses the principles of phenomenology. It was thought that this methodology would help to illuminate the effect of a family history of cancer within a palliative care setting whilst enabling the entire research process to proceed in an ethically appropriate manner. Phenomenology, alongside other qualitative methodologies, has been increasingly used to understand how individuals make sense of their experiences of illness and healthcare (Froggatt et al 2003, Borreani et al 2004). The potential of phenomenology to make a significant contribution to research within

palliative care is widely documented (Seymour and Clark 1998, Wright and Flemons 2002, Froggatt et al 2003, Borreani et al 2004, Kendall et al 2007). It was anticipated that phenomenology would present new ways of describing and understanding what it means to be a finite and situated human (Dreyfus 1994) when dying with a family history of cancer.

The principles of phenomenology appeared to be in harmony with the evolution of palliative care, which was based on listening to, and acting on, patients' perceptions of their own experience and needs (Saunders 2001). It was anticipated that consideration of the meaning and lived experience of the family history of cancer from patients' and nurses' perspective would be a first step to understanding how their family history affected their care needs.

### Paradigm

The concept of paradigm change was fundamental to this study. A paradigm can be defined as 'a conceptual or methodological model underlying the theories and practices of a science or discipline at a particular time' (OED Online accessed 1/9/07). The change in perception of cancer from a set of heterogeneous diseases linked by uncontrolled cell growth to a multifactorial disease of the human genome can be conceived of as a paradigm shift (Anderson et al 2000). A paradigm change is the transfer of allegiance from one paradigm to another leading to a conceptual and/or methodological change in the theory and practices of a particular discipline (OED Online accessed 1/9/07). This understanding derives from Kuhn (1962, 1996) who revolutionised the understanding of scientific development. He described how new discoveries are not integrated into the existing perception of the world but can totally change the worldview of an individual. Hence an individual who conceives of cancer as

a multifactorial genetic disease (i.e. within the genetic lens) may view a diagnosis of cancer, or the experience of a family history of cancer, very differently from someone who does not have this knowledge (i.e. outwith the genetic lens).

The concept of paradigm change has been influential throughout this study. It

- Underpinned the research aims: The whole study was designed around a belief that the knowledge of the multifactorial aetiology of cancer (with the implication that cancer was heritable) was an important change in worldview that could influence care need.
- Reinforced the ethical concerns that raising the issue of inherited susceptibility to cancer could cause distress, even to nurse-participants: Kuhn (1996) documents how being presented with a new worldview can cause intellectual bewilderment and even distress to practitioners as they question the basic principles and relevance of their work.
- Influenced the data analysis: Kuhn's (1996) description of the way different worldviews frequently co-exist during a period of paradigm change emphasised the need to be aware that different worldviews could influence how participants experienced their family history of cancer. The term 'within the genetics lens' is used to refer to care that specifically concerns issues associated with inherited susceptibility to cancer in this study. The term 'outwith the genetic lens' refers to practice where the heritable component of disease is not taken into account.
- Influenced the literature review: Kuhn (1996) emphasises that research must proceed from a research paradigm as without this it cannot cohere into an acknowledged body of knowledge (or be evaluated by other researchers). This thesis proceeded from within the genetics paradigm.

The concept of a paradigm has also been influential when distinguishing between different research approaches (Robson 2002). In research the concept of a paradigm acts like a net that contains the researcher's basic epistemological, ontological and methodological premises (Guba & Lincoln 1994). This research is firmly situated in the interpretivist paradigm: it is a qualitative study, concerned with how the family history of cancer is being interpreted, experienced and constituted in a palliative care context in the early twenty-first century.

However the scope of qualitative research undertaken within the interpretivist paradigm has grown out of a wide range of intellectual and disciplinary traditions and does not constitute or imply a unified code of philosophical understanding or set of techniques (Mason 2002). Hence the ontology, epistemology and philosophical understanding that underpins the hermeneutical phenomenological methodology adopted are discussed in more detail below.

### Ontology

Ontology is the branch of philosophy that is concerned with existence and the nature of those things that exist (Williams & May 1996). It is concerned with the structure of reality (Crotty 1998). The ontological understanding that underlies this study is realism; or what is frequently known as commonsense realism (Warburton 1995).

Commonsense realism assumes that there is an external world of physical objects that can be learnt about directly using the five senses (Warburton 1995). However the commonsense perception of phenomena has been challenged by empirical investigation and philosophical debate. Philosophers have long questioned whether objects even exist when they are not being observed (Warburton 1995). The ontology behind this study, however, does not deny the possibility of material existence; rather it questions

an individual's ability to know the world beyond our communal representations of it (Williams & May 1996). The ontology behind this study means that it is not concerned with the 'truth' behind any explanation for why certain families have multiple experiences of cancer but focuses on how the meaning of a family history of cancer was impacting the experiences of participants.

### Epistemology

Epistemology is the branch of philosophy concerned with how we know what we know and our justification for claims to knowledge (Williams & May 1996). It is important as it defines the principles and ways that knowledge can be demonstrated (Mason 2002), and the weight given to different types of evidence and how it is legitimised (Crotty 1998). The epistemology that underlies this research is social constructionism.

In a constructionist epistemology meaning is constructed by human beings as they engage with the world they are interpreting (Schwandt 1994). Knowledge is understood to be a constructive interplay between actual objects that exist and the meanings which occur when they are consciously attended to. For instance, a family history of breast cancer has been attributed to excess black bile, God's(s') judgement, contagion and shared lifestyle (Olson 2002). Meanings in the constructionist epistemology are bounded by the natural qualities of an object yet they only take actual meanings when consciousness engages with them (Crotty 1998). In social constructionism the focus is on how the world is known inter-subjectively: on the shared understanding of phenomena rather than on individual internal processes (Schwandt 1994).

Van Manen laments what he describes as the epistemological nihilism associated with the constructivist epistemology, saying 'it forces us always to see the relative,

historical, constructive and social character of truth at the expense of its deep hermeneutic facticity' (Van Manen 1990: 49). He states that the richness of phenomenology is that it speaks through lived experience and brings the phenomena into consciousness.

The epistemological and ontological underpinning of this study was congruent with using interviews to collect data. Interviews reflect the ontological belief that the experiences, understandings and interpretations of individual participants are meaningful properties of social reality (Mason 2002). In the social constructionist epistemology interviews are understood to generate situated knowledge (Mason 2002): that is, the interview data collected is acknowledged to be a reconstruction of events and experiences that is built between the participants and the researcher.

### Inductive Reasoning

Qualitative research was initially characterised by its opposition to the strict design characteristics of quantitative research and encouraged a pure inductive methodology where meaning emerged solely from in-depth exposure to the data (Silverman 2005). However, this naïve inductive approach has been criticised because it ignores the need for research to build a cumulative body of knowledge and ignores the reality that many studies, like this one, are focused around an orienting concept and/or interest (Miles and Hubermans 1994, Silverman 2005).

The study used inductive reasoning to analyse the data collected. Inductive reasoning 'is reasoning which goes from particular instances of a pattern to a generalised pattern' (Morton 2004: 434). Unfortunately there are inherent limitations in using inductive reasoning to understand and predict the world. This was first clearly

demonstrated by Hume (1711-1776) who showed that it was always possible for inductive reasoning to produce false results (Morton 2004).

Inductive reasoning is contrasted with deductive reasoning which begins with assumptions and shows that certain conclusions follow logically from these assumptions (Morton 2004). Hence a deductively valid argument is one where the conclusions always have to be true if the premises are true. However with induction there is always the possibility that further evidence could show that the inductive reasoning is false. Therefore even a reasonable conclusion obtained through inductive reasoning can never be proven with certainty (Morton 2004).

Nevertheless induction does have two important features that make it a useful way of examining the world (Morton 2004). Firstly, the knowledge gained by inductive reasoning must fit with the given evidence. It therefore does not allow conclusions or inferences to be drawn that go beyond the given evidence. Secondly, it aims to remove inconsequential detail and delineate core patterns within the given evidence. These two features mean that inductive reasoning continues to be considered an attractive and trustworthy method of reasoning about the world in which we live (Morton 2004).

### Phenomenology

Phenomenology is the study of phenomena (Crotty 1996). However phenomenology has evolved as a philosophical context for research (Lopez and Willis 2004) and two different approaches are commonly used within nursing. These are a) Husserlian Descriptive Phenomenology and b) Heideggerian Hermeneutic Phenomenology.

#### a) Husserlian Descriptive Phenomenology

Husserlian Descriptive Phenomenology was developed at a time when huge changes were going on in the scientific community and commonsense understandings of phenomena were being challenged by new discoveries and experimentation (Cahoone 2003). Husserl (1859-1938) aimed to consider the original phenomena that present themselves to our consciousness before we engage in systematic reasoning about them: to 'go back to the things themselves' (Velarde-Mayol 2000). His approach was descriptive (Van Manen 2002).

This approach did not deny or disclaim other scientific or philosophical understandings of objects, but claimed that they needed to be laid aside or bracketed if the meaning which attended to the experience of an object was to be understood. Husserl advocated bracketing to free the phenomenologist from preconceived ideas, irrespective of whether they originate from cultural tradition, empirical science or other authority (Velarde-Mayol 2000). Husserl did not deny that individuals had subjective reactions to, and/or received understandings of, phenomena, or that groups within societies commonly had intersubjective understandings of phenomena. Nevertheless he felt that the ultimate goal of phenomenology was to understand the essential essences of the objects themselves (Crotty 1996).

The research reported here has been influenced by Husserl's interpretation that phenomenology enables the identification of the essence of an object as consciously conceived. Use of phenomenology enabled the study to focus on the essence of a family history of cancer for palliative care patients. Whilst acknowledging the influence of Husserlian phenomenology it was not fully adopted because, as discussed below, the philosophical concept of bracketing was not thought to be possible or even necessarily desirable in this research.



## b) Heideggerian Hermeneutic Phenomenology

Heidegger (1889–1976) was Husserl's student. He developed Husserl's ideas (Moran 2000). He felt that the interpretation of the lived experience of objects could not be a neutral, theoretical or dispassionate contemplation, as advocated by Husserl, but must take into account the involvement of the enquirer themselves (Heidegger 1967, Moran 2000). Hence Heidegger rejected bracketing and sought to return to the things themselves, not as free-floating constructions or essences, but to consider them in the context in which they occurred (Crotty 1996). This has come to be known as hermeneutical or interpretive phenomenology.

Hermeneutics is the theory and practice of interpretation (Ree 1991). It originally applied to biblical criticism and the practice of reading religious texts with respect for the context in which they were written. It has migrated to other areas of scholarship as a practice of reading texts and human situations in the context that best brings understanding (Crotty 1998). It usually carries the implication that whilst some interpretations are better than others, none can ever be final (Ree 1991). Heidegger's phenomenology therefore aimed to be interpretive as opposed to the primarily descriptive practice of Husserl (Van Manen 2002).

A Heideggerian hermeneutic phenomenology was selected as the research methodology because it enabled an interpretive framework to be used to search out the relationships and meanings that knowledge and context have with each other (Streubert-Speziale and Carpenter 2007). This was congruent with the motivation of understanding the relationship between a family history of cancer and needs of patients with advancing disease within a cultural context where the awareness of inherited susceptibility to cancer was becoming more prominent.

Hermeneutical phenomenology was considered appropriate because it acknowledged that the research was deliberately undertaken from a particular stance that had a potential to enhance understanding (Crotty 1998). This was consistent with this study which arose from an intellectual and clinical stance that considered it important to be mindful of the effect inherited cancer was having within palliative care. It acknowledged that the study would engage reflexively with the concept of a family history throughout the research process, and that instead of preconceived ideas about their importance being bracketed out of the research process they were inherently included within it. The strengths and weaknesses of this approach for this study are discussed in Chapter Eleven.

### Phenomenology and Sample Size

In qualitative research the sample size is determined by the methodology selected and the topic under investigation, not by the need to produce generalisable findings. Phenomenological enquiry is essentially concerned with individual experience and uncovering the individual meaning of a phenomenon (Higginbottom 2004). Hence it may, in some cases, be appropriate to study a phenomenon from the perspective of a single participant (Miles & Huberman 1994). A single case study was not thought to be appropriate for this study for several reasons. Firstly, an aspect of the phenomenon under investigation, 'a family history of cancer', does not have a simple clearly defined definition. Secondly, because of the ethical issues discussed above it was not appropriate to ask participants directly about their family history of cancer. Too small a sample can lead to the data collected having inadequate scope to answer the research question (Richards 2005). This may be especially problematic when cases are only selected from either the centre or periphery of a phenomenon and can reduce the

understanding gained (Miles & Huberman 1994). Multiple cases add confidence to the data and strengthen the validity and the stability of the findings (Miles & Huberman 1994). However if the sample size in qualitative research is too large to allow for a deep, in-depth, investigation of a specific case it loses its *raison-d'être*: its prime focus, which makes qualitative research valuable (Van Manen 1990, Sandelowski 1995). Also, in research studies with high levels of complexity, data analysis can quickly become unwieldy with large sample sizes (Miles & Huberman 1994).

It was anticipated that a sample of between six and twelve participants from each participant category would give insight into the phenomenon, whilst remaining informative, manageable and achievable within the given research constraints. Van Manen (2002) suggests that this sample size is appropriate in conjunction with purposive sampling. Published qualitative studies by established research teams into psychosocial aspects of inherited disease frequently have larger sample sizes, however Miles and Hubermans (1994) suggest that when the sample size is greater than thirty a survey design is more appropriate, even when the resources of a research team are available.

### Reflection on the Choice of Heideggerian Hermeneutical Phenomenology

Heideggerian hermeneutical phenomenology was seen as an appropriate and tested methodology to use to make intelligible the lived experience of the participants who were dying with a family history of cancer. There were, however, two drawbacks to this choice. Firstly, as discussed (p35) it was ethically inappropriate to use the term 'family history' with patient-participants. This presented the challenge of designing a phenomenological study where it was not possible to mention the phenomenon under investigation directly. For this reason it is perhaps better to describe this study as using

the principles of phenomenology. Secondly, phenomenological investigation would primarily give insight into the meaning of the lived experience of a family history of cancer for participants. It was selected because it was thought this understanding was an appropriate first step to providing appropriate care to patients with concerns about their family history of cancer.

A limitation of Heideggerian hermeneutical phenomenology is that it would not produce an objective understanding of the effects of a genetic predisposition, which was independent of culture. Rather the aim was to objectively consider how the phenomenon of a family history of cancer was engaged with and constructed by the participants within British culture at a time when there was an increasing public awareness and scientific endorsement of cancer genetics. This limits the ways that the information obtained can be extrapolated (Green 2000), as the results need to be evaluated in light of researcher and societal bias (See Chapter Eleven). It intended to offer a plausible insight (Van Manen 1984) about the effect of a family history on patients to palliative care nurses, which could be used to inform the care of patients and families.

## **Conclusion**

This chapter has presented the ethical and philosophical underpinnings of the study. It describes how the sensitivity of the research topic and the vulnerability of the research participants were of prime importance from the outset. This influenced the decision to undertake an exploratory study of the phenomena. Heideggerian hermeneutic phenomenology was chosen for this study as allows the researcher to take a deliberate stance. This was consistent with the study rationale, which deemed it important to understand how a family history of cancer was affecting palliative care

patients in the context of genetic predisposition to cancer. How the philosophical and ethical foundations of the study were integrated into the research process is described in the next chapter.

## CHAPTER FOUR: THE RESEARCH PROCESS

*By wisdom a house is built and through understanding it is established.  
Through knowledge its rooms are filled with rare and beautiful treasures  
(Psalm 24:3)*

### Introduction

This chapter describes the methods of enquiry that were used during the study. The aim of the chapter is to provide a clear description of the research process so that the findings can be evaluated with regard to the methodological processes that underpin them. The key practical ‘real world’ constraints that affected the research process are also discussed.

### Defining the Research Question

An iterative process (Miles and Huberman 1994) was used to define the overarching research question ‘How does a family history of cancer affect the care needs of palliative care patients?’ that has guided this study. This was important as clear research questions are needed to provide meaningful information with which to develop nursing practice (Streubert-Speziale and Carpenter 2003). In qualitative research a clear question can prevent unfocused, overly descriptive studies (Mason 2002) and help ensure that appropriate data is collected to allow the researcher to consider the complexities and subtleties of the phenomena under investigation (Miles and Huberman 1994).

The research question was developed in conjunction with an initial review of the literature and of the ethical issues involved. The literature review was undertaken to learn what was already known about the topic (Silverman 2005). It helped ensure the study did not unnecessarily duplicate previous research (DH 2005) and was part of a

cumulative body of knowledge (Silverman 2005). It also determined that the study would be an original piece of work (Clifford 1997).

The process of defining the research question was started by brainstorming the different ways that cancer genetics might affect palliative care. These ideas were organised into groupings using a mind map (Buzan 1991). Initially the possibility of researching the needs of palliative patients with an identified genetic alteration which predisposed to cancer was considered. This was rejected because clinical experience suggested that concerns about familial disease were meaningful to patients and families who had not had previous contact with specialist genetic services. Practical concerns about recruitment were also considered. Consequently the decision was made to focus on people with a family history of cancer.

The research question first selected was ‘How does a family history of cancer affect the care needs of palliative care patients and their families?’ As indicated it was initially anticipated that the research would also directly investigate the experience of the relatives of palliative care patients. However, as the study progressed it became apparent that there were significant barriers to the recruitment of relatives into the study. These barriers are discussed in Appendix Three. To take this into account the final overarching research question became: ‘How does a family history of cancer affect the care needs of palliative care patients?’

Although it was recognised that palliative care is a multidisciplinary service it is acknowledged that each discipline has its own perspective on patient care (Doyle et al 2005). In focusing on care needs this research deliberately took a nursing perspective of the effect of a family history of cancer on patient care. This was because the study was motivated by experiences in clinical practice and a desire to better understand this

aspect of care. Nevertheless it was hoped that the study would have resonance for other healthcare professionals who work within palliative care.

The literature review showed this question addressed a gap in the knowledge base (Lillie 2006). Most of the existing research about the psychosocial implications of inherited cancer has focused on people who had attended regional specialist clinical genetics units to consider predictive genetic testing (Hallowell 1999, Hallowell et al 2003, Foster et al 2002a, b, Forrest et al 2003) and that there had been less investigation into the care needs of patients who had a family history of cancer but had not been referred to clinical genetics. The need for research to focus on the patient experience was emphasised by Hallowell et al (2004: 554). They state that ‘the fact that much of the research in this area (inherited susceptibility to cancer) has focused upon people at risk of cancer but who have no personal experience of cancer can be seen as an oversight on the part of researchers’.

As a result the aims and objectives developed were as follows.

### *Aims*

- To describe the experience of a family history of cancer on patients within a palliative care setting
- To understand the meaning of a family history of cancer for patients within a palliative care setting
- To understand how a family history of cancer affects the care needs of patients receiving palliative care
- To describe how qualified nurses perceive and understand the effect of a family history of cancer on the care of the family within palliative care



## ***Objectives***

- To review, analyse and critique the literature on the psychosocial affects of an inherited predisposition to cancer on patients with advanced progressive disease
- To explore the perceptions of a family history of cancer in palliative care patients
- To explore how nurses working in palliative care perceive and understand the care needs of patients and families with a family history of cancer
- To analyse the data obtained to understand the lived experience and meaning of a family history of cancer within the palliative care setting
- To discuss the implications of the study for the provision of appropriate palliative care

## **Designing the Research Study**

Prestructured, well-delineated designs provide clarity to qualitative research studies and help ensure that relevant data is collected (Miles and Huberman 1994).

Pragmatically a considered and appropriate research design was necessary to allow the researcher to request and obtain access to terminally ill research participants. The study design developed was single, semi-structured recorded interviews with a purposive sample of six - twelve hospice patients who had a family history of cancer, and six - twelve hospice nurses. All the participants were recruited through a hospice that agreed to participate in this study.

### Design of the Interview Proforma

As discussed (p49) the choice of phenomenology had one specific drawback in the context of this study: the sensitivity of the research topic. There was a genuine

possibility of causing emotional distress to participants with advancing incurable disease, through the introduction of the concept of predisposition to cancer within their family. Consequently it was not ethically appropriate to ask patient-participants directly about how they were affected by the potential that their cancer could be inherited. A major design challenge was designing a study that would reveal pertinent and meaningful information about the effect of a family history of cancer without directly enquiring about inherited genetic predisposition to disease, a focus of interest for the study.

The construction of the interview proforma was an important part of this process as it determined what data would be collected (Holstein & Gubrium 2004). The interview process needs to be disciplined and focused around the fundamental question that prompted the research (Van Manen 1990). In this study the main challenge was to design an interview proforma which would yield relevant and meaningful data about the effect of a family history of cancer, whilst minimising the potential that the interview would raise new fears about genetic disease and the potential consequences of this for the participant's family. Separate interview proforma were constructed for patients and nurses (Appendices Four and Five). They were constructed during a three stage process.

1. Initially direct open questions about how the family history of disease and the potential for an inherited genetic predisposition to cancer were affecting palliative care patients were considered. This process clearly delineated the type of information that the researcher hoped to uncover through the exploration of patients' views. However the questions were unsuitable for use with patients in this format due to the potential for causing emotional distress. The proforma for the nursing interviews was however completed at this stage.

2. The second phase consisted of an attempt to reconstruct the interview questions for patient-participants into a suitable format. It was, however, decided that even commonly used medical or colloquial language like ‘family history’ or ‘in the family’ had the potential to provoke distress in the context of terminal disease. Furthermore, it became increasingly apparent that the sensitivity of the research topics and the diverse ways that families could be affected by their family history of cancer meant that pre-constructed formal questions would be a blunt tool with which to obtain relevant information.
3. As a result a semi-structured format (Robson 2002) was developed. It was decided to focus the interviews around three key themes that related to familial cancer. These were developed from the questions considered in stages one and two. They were:
  - Theme One: Previous experiences of cancer within the family
  - Theme Two: Understanding of cancer
  - Theme Three: How the participants felt that their care needs were altered by their previous experiences of cancer within their family and their understanding of cancer.

Although there were a series of pre-determined prompts to guide the research interviews within each theme, it was anticipated that these would be modified or omitted depending on what seemed most appropriate during the interview (Robson 2002). That is, they were topic drivers rather than formal questions. Nevertheless an opening introductory question was used to open all the patient interviews. It was intended that the introductory question would allow the researcher to be guided by the participants’ language and response when formulating questions around the themes (Robson 2002). For instance, the question ‘*What do you understand about the aetiology*

*of cancer?*' (I10) was used with one participant, Jenny, who described herself as having *a grade four adenocarcinoma* (Jenny), whilst the phrase '*Where do you think your cancer came from?*' (I5) was used with another, Ezra, who had stated that he did not like medical language and had chosen not to discuss his cancer with doctors.

The use of key themes and prompts utilized the flexibility and adaptability of individualised face-to-face interviews (Robson 2002). It had the advantage of enabling the researcher to ensure that the interviews covered the same topics and obtained comparable responses, whilst allowing for the development of conversation between the participant and the researcher to give rich and thick data (Wisker 2001). The interview proforma did not contain a highly structured sequence of questions to obtain standard biographical data. This was intended to help the interviews feel like a conversation with a purpose (Burgess 1984), and to encourage the participants to speak freely about their experiences from their perspective (Robson 2002).

The researcher had to minimise the potential that the interview would provoke new or unnecessary distress about the participants' own anticipated death (Kendall et al 2007). Hence the prompts within the proforma focused on the participants' past and present circumstances. The participants were not asked about the future actions they or their family members might make, in the hope that this would prevent the interviews from leading the participants to think about their own future dying process when previous deaths within the family were discussed.

Consequently, the design of the interview proforma, with the deliberate omission of direct questions or prompts about cancer genetics or family history of cancer, was a compromise between the underlying impetus for the research and the ethical requirements of the research process. This compromise had two major consequences. Firstly, it meant that it was known from the outset that the data collected might focus on

the effects of previous experiences of cancer within the family rather than on the effect of a genetic predisposition to disease. It was recognised that what was not said could be as meaningful as what was said: for example, it was thought that it would be noteworthy if the topic of inherited genetic predisposition did not emerge from the interviews. The second consequence was the need to be constantly alert during the interviews to ensure that questions focused on the three central themes and that the prompts used did not promote new fears about a genetic predisposition.

The validity of a single qualitative interview has been questioned as the researcher may make unwarranted assumptions that they share a common perspective with their participants (Angen 2000). Returning the transcripts to the participants to read to allow them to confirm whether they have said what they meant to say is recommended to prevent this. It also gives participants the option of withdrawing statements with which they are not comfortable (Angen 2000). However, the review of a verbatim transcript where oral language can appear incoherent or confused can provoke shock (Kvale 1996) and leave participants feeling that they have been portrayed as having a lower level of intellectual functioning (Dearnley 2005). It was thought this could be especially distressing due to the sensitivity of the interview content. However, in this study, the decision to use a single interview design was primarily pragmatic. It was taken because there was the potential for significant deterioration or death in hospice patients over short periods of time and it was thought that returning transcripts to patients might not be practical or helpful.

### Selecting the Study Setting

The decision to complete the research through the auspices of a hospice that provided specialist palliative care services (NCPC 2007) was taken early in the research

process. It was considered the best location to obtain the sample group required for the study (Borssteede et al 2006). The participating hospice provided in-patient services, a day centre and specialist community services. Sampling of a single organisation is clearly not representative of the broader world due to the potential introduction of unspecifiable biases and influences into the research (Robson 2002). The decision to access all the participants through one participating hospice was taken in the knowledge that it would limit the trustworthiness of the data to provide general recommendations for patient care. It represented a compromise between the ideal and the practical resource limitations of this project.

#### Selecting an Appropriate Sampling Strategy

A purposive sampling strategy was selected. This is a deliberate, non-random method of sampling which aims to access participants with a particular characteristic (Bowling 2002). Although purposive sampling does not provide an empirical representation of the wider world, it enables the researcher to obtain a relevant and strategically chosen sample that covers an appropriate range of contexts to build a well-founded argument (Mason 2002). Hence data obtained from a purposive sample can be used to increase the insight into specific social phenomena, but cannot be used to make generalisations about the general population (Green 2000). It is easy to use and has a good response rate (Bowling 2000).

Purposive sampling requires that the research design clearly and critically delineates the parameters of the sample (Silverman 2004). Two sample categories were selected with the expectation that they would provide different perspectives on the effect of a family history of cancer and allow cross-contextual comparisons of the data to be made.

The categories were:

- Hospice Patients: Hospice patients who had a diagnosis of cancer, and who had at least one first or second degree blood relative who had died from cancer could participate in this study
- Nurse Participants: Qualified nurses who were employed by the participating hospice and had at least one years experience working in palliative care and/or oncology could participate in this study

A deliberate decision was made to include patients who had a cancer with a clearly identified genetic component (like breast cancer), as well as cancers where there were no identified predisposing genes. Similarly the decision to use the broadest definition of family history of disease (at least one first or second degree blood relative) was taken because it was hoped that this would indicate whether people who were at low risk of a genetic predisposition were also concerned about this issue. The principle inclusion and exclusion criteria for patient-participants are given in Table Four (see below p62).

It was recognised that palliative care is a multidisciplinary service. However each discipline has its own needs (Doyle et al 2005). There is an identified need for nurses to re-examine the knowledge base that is required for nursing practice as the scope of genetics extends to include multifactorial diseases like cancer (Anderson 1999, Frazier et al 2004). This is to ensure that there are no gaps in knowledge that would limit the evidence base of clinical nursing when dealing with patients and families concerned about genetic illnesses (Donaldson 1999). Hence it was decided to focus on a nursing perspective, although it was hoped that the study would be meaningful for other health care professionals who work within palliative care.

**Table 4: Inclusion and Exclusion Criteria for Patient-participants**

<p><u>Inclusion Criteria</u></p> <ul style="list-style-type: none"><li>• Participants were patients of the participating hospice</li><li>• Participants had to be physically, mentally and emotionally fit for interview and able to give informed consent. This was assessed by designated hospice staff</li><li>• Participants needed to be able to speak fluent English. This was primarily because there was no budget for an interpreter and because the presence of an interpreter might alter the dynamics of an interview. Equally it was not known what information about the causes of cancer were available to non-English speakers. It was highlighted to hospice staff that participants from all ethnic minorities were invited to participate in the interview as long as they spoke English</li></ul> <p><u>Exclusion Criteria</u></p> <ul style="list-style-type: none"><li>• No participants under Eighteen</li><li>• No participants who were actively participating in other research studies</li></ul>
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### Designing the Participant Recruitment Protocol

Recruitment into research studies in a palliative care setting is known to be difficult and many local and national studies have been abandoned due to poor recruitment (Ross and Cornbleet 2003, Addington-Hall 2002). This is variously attributed to the perceived ethical challenges of research with the dying (Jubb 2002) and the physical frailty and rapid deterioration associated with advanced terminal disease (Ross and Cornbleet 2003). Hence considerable attention was given to appropriate ways of recruiting patients to this study (See Appendix Six).

The sensitivity of the research alongside the vulnerability of palliative care patients meant that it would have been inappropriate to approach all the patients within the hospice about the study. To minimise the potential for harm there was a clearly defined



protocol for the: a) identification, b) initial approach and c) recruitment for all participants.

#### Patient-Participants

- a) Identification: Designated hospice staff were asked to identify potential patient participants for this study. These nurses were referred to as 'link nurses'. This helped ensure that only people who were physically, emotionally and mentally fit for interview and who were able to give informed consent were approached to participate.
- b) Initial Approach: The hospice staff were asked to give potential patient-participants an information sheet and an introductory letter (Appendix Seven & Eight). Community patients were asked to complete a reply form (Appendix Nine) indicating how they wished to be contacted. This was returned by post. A stamped addressed envelope was included.

It was recognised that asking hospice staff to distribute the participant information leaflet meant that there was the potential for confusion between the function of the research and the care-giving role of hospice staff. Seymour & Ingleton (2005) suggest that some patients may feel obligated to participate in research in gratitude for the care given or through wanting to please their caregivers. This may be especially true in the supportive environment of a hospice where the social, emotional and spiritual aspects of cancer and dying may have been addressed for the first time (Calman & Hanks 1998). Hence care was taken to ensure that there was a distance created and kept between the research process and the hospice care-giving activities. All written information about the research was headed by the University logo and all hospice link staff

were asked, verbally and in writing (see Appendix Ten), to ensure that all potential participants were aware that the researcher worked for the University and was not part of the care team at the hospice. Hospice staff were asked to emphasise at all times that participation was voluntary and that the care of potential participants would not be affected in any way by their decision to participate.

- c) Recruitment: The researcher contacted potential participants at least twenty four hours after she was informed by hospice staff that they were interested in participating in the study. This was to ensure that all potential participants had time to read the information leaflet, which included an outline of the themes that would be covered during the research interviews. This allowed potential participants to reflect on whether they wished to participate and formulate any questions they had about the research process. As people with terminal illness frequently experience rapid change in their cognitive function (Rees 2001) staff were asked on the day of interview whether they still felt that potential participants were able to give informed consent.

### Nursing Participants

The internal post was used to deliver a covering letter and information leaflet to all the qualified nurses working at the hospice. Nurses who considered participating in the study were asked to initiate contact using a reply letter (see Appendix Nine), or by telephoning the researcher. This meant that the researcher did not directly approach any nurse personally to request their participation in the study. This was intended to reduce any potential pressure on nurses to participate. Interviews occurred at least twenty-four

hours after the potential nurse-participant contacted the researcher so they could consider any extra information received.

## **Obtaining Approval for the Study**

### Ethical Approval

Ethical approval for the study was obtained from the appropriate NHS local research ethics committee (LREC). It was accepted with minor modifications (LREC Number: 05/Q2707/146). However two of the modifications that were required by the LREC directly impacted on the research data obtained. Firstly, LREC felt that due to the sensitivity of the research topic and the vulnerability of the research participants, it was inappropriate for the researcher to directly ask participants whether they were able to discuss their understanding and experience of cancer with the younger generation of the family. Hence the prompts in the final interview proforma (see Appendix Four) ask more generally about discussions within the family. No specific questions were asked about the younger generation of the family unless the topic was first raised by the research participants. The second modification that affected the study concerned the potential recruitment of relatives as indicated above (See Appendix Three).

### Negotiating Access

The research proposal was submitted to the hospice research steering group. The main concern raised by this committee involved the systems in place to support any participant if the research interviews provoked distress. A meeting with the hospice social work manager was organised specifically to address this issue. It was agreed that all participants would be given the contact details of the hospice's own counselling team, as well as the details of an external organisation, in case they wished to further

explore any of the issues raised in the interviews. If appropriate participants would be linked with the regional clinical genetics unit so they could rapidly access specialist support.

Permission to proceed with the study was contingent upon maintaining the anonymity of the research participants, a right which is enshrined in law under the Data Protection Act (1998). Reassurance was given that the name of the participating organisation would not be mentioned in any published data and that identifying details about participants would be anonymised. Throughout the research process care has been taken to balance consumers need for contextual information with the ethical/legal requirement to maintain anonymity.

Prior to commencing the research study the project was introduced to the hospice staff. Five separate presentations were made to general ward staff, community staff, day centre staff, medical staff and the social work team. This was useful as it enabled the researcher to discuss the inclusion criteria, the interview proforma and ethical issues with staff prior to the commencement of the project, complementing the written information provided (Appendix Seven).

## **Data Collection**

Interviews have been described as ‘conversations with a purpose’ (Burgess 1984: 102) and can be considered to be a social situation much like any other human interaction (Mason 2002). The interviews for this study were structured interactions. Each one began with a review of the main themes of the interview followed by the completion of a written consent form (Appendix Eleven), before the tape recorder was switched on.

Within the constraints of the research process, every effort was made to promote a relaxed atmosphere during the interviews. They occurred in a side room situated within the participating hospice or within the participant's home. The room in the hospice was well-decorated with comfortable seating and natural light. It was a familiar environment to the participants as they had previously used it for other activities. Participants often had a cup of tea perched next to the tape recorder. The researcher wore smart casual outfits.

The way an interviewer is perceived by a participant can affect the information obtained (Robson 2002). It was therefore important to consider both how the researcher would be introduced to the patient and nurse participants and to think about how this might affect the interview process. The participants were first introduced to the researcher through the introductory letter (Appendix Eight). This informed them that the interviewer was a nurse by background but the emphasis was always on her role as a researcher from the University. Patient-participants were not informed that the researcher had considerable experience of working in palliative care. This was to try to ensure that participants did not see the interviews as an alternative source of care and to enable the researcher to separate her role as a palliative care nurse from her role as a researcher. Prior to the interview the researcher was introduced to patient-participants as a researcher from the University by a nurse from the hospice. This both reaffirmed that the participating hospice supported the project but emphasised that the researcher was separate to the hospice. The nurse-participants were aware that the researcher was a palliative care nurse. The effect of this on the research findings is discussed in Chapter Eleven.

The need for research interviews within palliative care to leave participants in a safe emotional state has been emphasised (Kendall et al 2007). After the tape recorder

was switched off it was acknowledged that the research discussion had covered areas that some participants might have found difficult. The process for obtaining ongoing support was explained verbally and in writing. It is good practice to thank people for their participation in research (Chapple 2006). All participants were thanked at the end of the interview. This was followed by a handwritten thank-you card, as this had been especially appreciated by participants in a similar study (Grinyer 2004).

### The Research Participants

Twelve patient-participants and ten nurse-participants were recruited into the study. The patient-participants consisted of six men and six women. Of these one was single, two widowed, and nine married. Their age ranged from the mid-forties to mid-seventies. Two of the male participants described themselves as Black-British, both born overseas in the Caribbean. Although participants were not asked about their socio-economic background most participants spontaneously mentioned their occupation. These included housewife, refuse collector, cook, heavy vehicle driver, musician, council worker, administrator and self-employed business women. Three of the participants commented on their lack of formal education and no participant mentioned going to university. They all lived within the diverse urban catchment area of the participating hospice.

The purposive sampling method ensured that all participants had been diagnosed with incurable cancer and had been predeceased by a first or second degree relative from cancer. No attempt was made to select participants according to any other biographical factors. It is known that several participants died whilst data collection was ongoing, confirming the advancing nature of their disease. The patient-participants have been assigned pseudonyms with a brief anonymised biography. These contain

contextual biographical detail about the participants' family history of cancer. They are very basic to ensure the anonymity of patient-participants and their families.

The nurse-participants were all female, white, qualified nurses with between one and twenty years working within a specialist palliative care and/or oncology setting. They included four ward nurses, two day centre nurses and four community palliative care nurses. To preserve the anonymity of the nurse-participants personal details have not been reported.

### The Knowledge Generated through the Research Interviews

Interviews that are undertaken for clinical reasons have a very different purpose than those undertaken for qualitative research (Britten 2000). The clinical task is to use the interview to fit a situation or problem into an appropriate category in order to choose an appropriate management strategy. In phenomenological research the aim is to discover the participants' own understanding of a situation (Britten 2000). Research interviews can also be viewed as social encounters during which knowledge is actively constructed (Holstein & Gubrium 2004), or at the very least, reconstructed within a specific context and situation (Mason 2002). Consequently the researcher was aware that the participants might not just be describing their family history and the meanings that these events had for them but actively selecting a particular narrative or way of reconstructing events for the purpose of the interview.

This view was reinforced by the first response to the first question during the first interview.

*Researcher: So my opening question is, can you tell me about yourself and your experience of cancer?*

*Participant: What do you want to know about me? Just my illness? (Anne)*

That is, the first participant interviewed clearly asked that the terms of the research interview be made more explicit, specifically whether the locus of the information given should revolve around her experiences as a person with cancer or whether she could present a broader more holistic picture of herself and her life experiences. Other participants also showed their awareness that the interviews were orchestrated encounters for the production of situated knowledge by regularly checking that they were giving information that was relevant to the research study.

*Is that the sort of thing you want? (Grace)*

*Are you sure you want to hear all this? (Jenny)*

Similarly several participants (especially nurse-participants) explicitly indicated that the interview was causing them to re-evaluate their experiences and not just recall them.

*I hadn't thought about it till now ... On reflection now, perhaps not at the time ... on reflection I think that ... (NP3)*

That is, some participants acknowledged that the interviews were causing them to reconstruct their understanding of events rather than just recall them. Other participants appeared to enjoy the research interview as it gave them the chance to simply recall past events and talk about the meaning these events had for them in their present circumstances. Hence the data on which the analysis is based was both recalled and generated (Mason 2002) during the research interviews.

### The Research Interviews: The Researcher's Perspective

It was apparent from the first interview that the interviews had the potential to be revealing, sensitive and distressing for the researcher. The research interviews with patients were challenging due to a) the emotional content of the interviews, b) the physical frailty of the participants and c) technological mishaps.



a) The emotional content of the interviews: It had been anticipated that the interviews, which focused on previous experiences of cancer within families would be sensitive but the full extent of the emotional impact of the interviews had not been anticipated. This was partly due to an ongoing discomfort, which was associated with the information gathering aim of the research interview as opposed to the care management aim of a clinical interview (Britten 2000); but also due to the content of the interviews. Inherited genetic predisposition to cancer is associated both with multiple experiences of cancer in individuals and families and with experiences of cancer at a young age. Hence many participants had experienced multiple deaths, including deaths of parents when they were children, deaths of siblings in young adulthood, and deaths of children, nieces and nephews. This had been anticipated but the full range of consequences for the participants had not. The interviews ranged over sensitive issues including childhood abuse, adoption (both being cared for by other family members and the demands of adopting family members), suicide and euthanasia. Lastly, during one interview the researcher felt that the interview had raised/exposed fears about the possibility of inherited disease and the potential implications for the interviewee's children. Due to the emotional demands of the interview, a small advisory group was set up to allow the researcher to discuss, in a confidential forum, the research experience. This comprised an experienced nurse-researcher and psychologist-researcher.

b) The physical frailty of the participants: One interview was stopped by the researcher because the participant was frail, in pain and fell asleep during the interview. It was decided to include the data from this interview in the research as the participant, despite being ill, wanted to participate and to use her story to '*give something back*' (Grace). Nevertheless physical frailty did limit the participant's ability to fully

contribute her experience to the study (Chapple 2006). Three interviewees had speech impediments due to concurrent disease, cancer or as a side effect of treatment. This significantly increased the time required for transcription.

c) Technological difficulties: Good recording equipment is essential when interviewing people with terminal illness as people who are seriously ill cannot always talk loudly or clearly (Chapple 2006). Unfortunately on one occasion the digital recorder failed (interview with Claire). However, full notes were written up following the interview (within four hours) and it is thought that all the major themes of the interview were accurately recorded. These were included in the data analysis although verbatim quotes were not available for illustration in the analysis.

It is tempting to make assumptions about the meaning of being a participant in research (Grinyer 2004). However no systematic attempt to evaluate the research experience from the participants' perspective was made in this study. Several participants spontaneously mentioned that they had enjoyed being listened to courteously, whilst others clearly wanted their experiences to be used to help other families who had had multiple experiences of cancer. Nevertheless it is known that the interview actively provoked distress in one participant. The hospice staff supported this participant using the systems designed when they agreed to take part in the study (see p65). They sought feedback from this participant about whether the research should continue. He is reported to have said that he felt it was appropriate and that he would choose to be interviewed again. Frank (1997) suggests that telling their story can help people construct narrative accounts of their illness and find healing in the process. Hence it is hoped, but not known, that the interviews did not cause any ongoing distress.

### Completing Data Collection

One important task within qualitative data analysis is the decision about when the data collected provides access to enough data, with the right focus to enable the study to answer the research question (Mason 2002). This point is usually termed ‘data saturation’ (Morse 1995, Robson 2002). However, due to the inductive nature of qualitative research, it always remains possible that new evidence could alter the conclusions drawn (Morton 2004). Consequently the concept of saturation is contested. It has been suggested that it may be a myth (Streubert-Speziale and Carpenter 2003) and that the best outcome that can be hoped for is saturation of a specific phenomenon at a particular time and location. Van Manen (1990) suggests that phenomenological description is never complete but ‘only an example, an icon that points at the thing which we attempt to describe’ (Van Manen 1990: 121). He emphasises that the nature of human experiences are as infinite and varied as humanity itself.

This research was undertaken in the belief that saturation was a philosophically flawed concept. As discussed (p44) quantitative data analysis is based on inductive reasoning, which means that there is always the potential for new evidence to show that the inductive reasoning is false, irrespective of sample size (Morton 2004). However the concept of saturation was a useful heuristic tool in deciding that there was adequate data to answer the overarching research question ‘How does a family history of cancer affect the care needs of palliative care patients?’ albeit within the participating hospice in 2005/2006 whilst data collection occurred. Morse’s (2000) exposition of the assumptions underlying the concept of saturation was helpful. She suggests that the size of a study is determined by five factors: the use of shadowed data, the scope of the study, the quality of the data, the nature of the topic, and the study design. Three of

these factors were especially important in deciding that an appropriate amount of data had been obtained.

- The Use of Shadowed Data: Shadowed data refers to data where the participants are talking about the experiences of others, and how their own experience resembled or differed from the experience of others (Morse 2000). In this study the patient-participants were discussing their relatives' experiences of cancer alongside their own. The nurse-participant data also provided copious shadowed data that both enhanced the analysis and helped verify the emergent themes. This 'shadowed experience' (Morse 2000: 4) is particularly important in obtaining an understanding of the range and domain of a phenomenon.
- The scope of the study: In general the narrower the focus of the study the more rapidly the data becomes saturated (Morse 2000). This study was designed around a clearly defined, overarching research question. No new information was collected about the way the family history of cancer was affecting the care needs of patients within the participating hospice at the time the study was undertaken – before data collection was discontinued. (For instance, no new information was learned from the final three nurse interviews). Nevertheless continuing data collection beyond this point gave a deeper appreciation about the way people could be affected by the phenomenon of a family history of cancer and allowed recurrent discussion of emergent themes which broadened the understanding of the phenomenon and increased the validity of the study.
- Quality of data: Morse (2000) discusses how some participants are able to reflect on a topic and express themselves more clearly than others. She notes that fewer participants are required when an appropriate sampling strategy targets participants with the appropriate experiences and are willing to share

them with the researcher (Morse 2000). The purposive sampling used in this study was effective in locating participants who were both dying with a family history of cancer and who were willing to discuss this experience. Consequently the data obtained was rich, experiential and informative.

## **Data Analysis**

Gaining insight into the essence of a phenomenon involves a process of clarifying and of making explicit the structure of meaning of lived experience (Van Manen 1990). This was accomplished using qualitative data analysis, which is characterised by its attempt to analyse language with the aim of understanding the way that experiences are re/constructed, described and made meaningful (Gibbs 2002).

Confidence in this process is enhanced by a systematic and structured approach to obtaining meaning from qualitative data (Miles and Huberman 1994). Therefore the process of data analysis was structured in accordance with established, well-documented methods of analysis. Miles and Huberman's (1994) framework was used to complete a content analysis using an iterative approach where codes emerged from the participants' experiences. Miles and Huberman's (1994) framework describes three concurrent flows of activity: data display, data reduction and conclusion drawing and verification. However in phenomenology it is necessary to go beyond content analysis to develop a nuanced understanding and description of the lived experienced (Hsieh and Shannon 2005). This was accomplished using Van Manen's (1990) schema of 'lifeworld existentials'.

### Thematic Analysis: Data Display

The first step in data display was transcribing the interviews then repeatedly reading the transcripts to obtain an overall sense of the phenomenon (Hsieh and Shannon 2005). The data was then coded using a content analysis approach as this allows the categories to emerge from the data. Simple data analysis is a particularly useful analytical method when there is limited existing research or theory about a phenomenon (Hsieh and Shannon 2005).

The initial codes were descriptive but these became more conceptual and interpretative as the analysis progressed (Miles and Hubermans1994). For instance, ten descriptive codes emerged from the initial coding of the patient data about the causes of cancer. These were

- CC-(cancer cause)-bereavement
- CC-diet
- CC-environment
- CC-genetic
- CC-iatrogenic
- CC-lifestyle
- CC-other
- CC-smoking
- CC-stress
- CC-unknown

These initial codes were revised as the analysis progressed (Miles and Huberman 1994).

- The cc-smoking, cc-diet and cc-lifestyle codes were merged into one code named cc-lifestyle
- The cc-bereavement and cc-stress codes were discontinued. They both had very little data (each from a single participant). The data within these codes was recoded into a code that was emerging as conceptually more meaningful (Miles

and Huberman 1994). Hence the bereavement data was recoded into a node about the effect of previous familial deaths.

- The cc-other code was large. On close examination it became clear that the data could be sub-coded. It was apparent that some explanations had their origins in historical scientific theories. These were re-classified as cc-historical. Others appeared to be idiosyncratic environmental explanations for cancer and were recoded as cc-environmental-idiosyncratic and became a sub-code of cc-environment.

Coding is not just segmenting data but the act of dissecting transcribed data into meaningful segments whilst maintaining the relationships between the different parts (Miles and Huberman 1994). The use of a computer software package NVIVO helped maintain the link between coded material and their context within the interview transcript throughout the project. The process of recoding continued until it was felt that all the information had been placed in a conceptually appropriate code.

Family trees were also constructed from the data obtained from the interviews as they are a succinct means of displaying information (Skirton and Patch 2002). However, as the study did not aim to assess whether participants had a genetic predisposition to cancer, no attempt was made to systematically collect information for this purpose. For instance, there were no probes about the cause of death of aunts, uncles or grandparents, nor was information obtained about unaffected siblings or other relatives. Hence the family trees (see Appendix 13) are incomplete and probably contain inaccuracies.

## Data Reduction

The first step in data reduction occurred after all the interview material had been coded. The data was reduced to information that was relevant to answering the research question. In practice this meant deliberately extracting codes of data from the analysis. There were three subsets of repeatedly occurring data that were systematically removed from the data.

- Information about the participant's experience of treatment (surgery, radiotherapy and chemotherapy)
- Information about living with the symptoms of advanced incurable cancer (e.g. pain, nausea, tiredness, poor mobility)
- The relationship with healthcare professionals during the participant's cancer journey

There were also two interrelated areas where it was particularly difficult to decide whether or not to include the data. This was information about the non-cancer deaths of family members and the deaths from cancer of non-relatives. These deaths had often had a significant impact on how the participants viewed the cancer within their family and therefore impacted on the phenomena of interest. Nevertheless this was not the focus of this study. In practice an individual decision was taken in every case depending on how the participants associated the deaths with their own and/or their family history of cancer. Hence the fact that a mother thought that the aetiology of her cancer was associated with the (non-cancerous) death of her son was included. Two participants discussed suicide within their family at length; one was included as the suicide had direct relevance to her present 'lived-experience', whilst another participant's concern that his brother had committed suicide due to a particular incident was not. Although this incident had significantly influenced the participant's attitude



towards his family and affected his experience of family whilst dying, it did not directly relate to the phenomena under investigation.

A final key step in data reduction was the selection of appropriate text for display. The aim was to find examples that pithily summarised the key issues that arose from the interview data whilst ensuring that all the participants' voices were heard. However some participants were more articulate than others and the lucidity of the text was the final arbitrator of which quotes were included in the thesis. On occasions, extracts from the interview transcriptions are included. This occurs when the meaning of the participants' comments is more clearly understood in the context of the interview. In these extracts the researcher's 'voice' is indicated by (I), to signify interviewer.

### Conclusion Drawing And Verification

The third concurrent activity in Miles and Huberman's (1994) framework is conclusion drawing and verification. This was started by considering the data contained within each code. The aim was to understand the underlying patterns and explanation for the relationship between these patterns to express new ideas about the phenomenon (Richards 2005) whilst maintaining openness and scepticism about any conclusions drawn (Miles and Huberman 1994).

Codes were clustered into groupings that had similar patterns and characteristics (Miles and Huberman 1994). The data within these clustered codes was re-examined to look for common emergent themes and conceptual relationships. For instance, within the cc-cancer cause nodes discussed above it became clear that the core emerging themes contained within the coded data was scepticism about the given causes of cancer and the limited understanding of the causes of cancer displayed. (See Chapter Seven).

As the analysis progressed the relationships between the different clustered codes became more conceptual and interpretative (Miles and Huberman 1994). For instance, there were five code-clusters that brought together data about the different ways that the participants had been affected by people dying at a younger age than normal. These were

- Parental death in childhood
- Death of a young sibling
- Death of nieces and nephews
- Death of own children
- Dying young

The five code-clusters were reflexively analysed. That is, the information within the cluster-codes was read repeatedly whilst asking questions like ‘What is this about?’, and ‘What does this mean?’ (Morse 2008). It became clear that there were several common themes that emerged throughout the data. For instance, the cluster codes above all contained information about

- The effect of young adult death on children/childhood
- Communication issues when a young adult is dying
- Changes to family structure due to young adult death

The relationship between these ‘common themes’ and the rest of the data was then considered. For instance, was there a difference between the data about communication in young adult death and older individuals in the family? Were the themes verified by the nurse-participants identifying it as an issue that affected care? The common themes that emerged from the clustered codes were linked using Van Manen’s (1990) schema of ‘lifeworld existentials’ to systematically describe the phenomenon of the family history of cancer for palliative care patients.

Visual displays and mind-maps were a useful heuristic device for exploring the relationship between the different codes throughout the analysis (Buzan 1991). At their simplest matrix tables of the different participants' experiences helped ensure that all relevant material remained contextualised during the analysis (Miles and Huberman 1994). More complex thematic diagrams were also used to assist in the understanding of the relationships between the different codes facilitating the development of themes (Appendix Twelve).

The process of conclusion drawing and verification is also an iterative process within Miles and Huberman's (1994) framework. Verification started during data collection. For instance, as the patient interviews progressed it emerged that for many participants the experience of earlier multiple primary cancers and the younger age that relatives had died had greatly impacted on them. To help verify these findings specific prompts about these factors were added to the nurse-participant interview proforma. This process continued throughout the research process (see Chapter Eleven).

#### Lifeworld Existentials as a Guide to Reflection (Van Manen 1982, 1990)

The challenge of phenomenology is to go beyond a content analysis to develop a nuanced understanding of the lived experience and meaning of a phenomenon (Hsieh and Shannon 2005). This was achieved using Van Manen's (1982, 1990) concept of phenomenological existential analysis, which provided a systematic way of reflecting on the structures inherent in the experience of a family history of cancer for palliative care patients. It allowed the emergent themes to be discussed in a systematic, structured and meaningful way. It identified the way the family history of cancer related to four existential themes that pervade the lifeworld of all human experiences irrespective of their cultural, social or historical significance (Van Manen 1990, 2002). These

existential themes are lived body (corporeality), lived time (temporality), lived human relationship (communality) and lived space (spatiality).

- **Lived Body:** The bodily experience of cancer and death within the family was central to the patient-participants' data. Focusing on the participants' corporeal experience of cancer ensured that the analysis considered the nature of the cancer and deaths from which their lived experience arose. As discussed in Chapter Three one inherent difficulty in phenomenology is the difficulty of isolating the lived experience of a phenomenon from the essence of a phenomenon under investigation. The corporeal analysis facilitated consideration of the essence of the participants' experience (See Chapter Five).
- **Lived Relationship:** This relates to the way that relationships are maintained with others (Van Manen 1984). The patient-participants focused on how family relationships were affected by previous deaths within the family and how this affected their present experience of living and dying (See Chapter Six).
- **Lived Time:** This refers to the subjective experience of time as opposed to chronologically measured time. It is the temporal experience of being in the world (Van Manen 2002). For the participants this involved reflection on how the past influenced the present, as well as the projection of hopes and fears for their family in the future (See Chapter Seven).
- **Lived Space:** The study occurred within a hospice, an institution where patients receive support for living and dying with advanced incurable illness. This chapter focuses on the nurse-participant data as only the nurses were asked directly about the phenomenon of caring for patients with a family history of cancer in the context of terminal disease (See Chapter Nine).

Heidegger (1967) emphasized that people cannot abstract themselves from their understanding of the world (Lopez and Willis 2004). Hence information about the patient-participants' understanding of cancer has been included in this study. This information, which links to the way the lived experience was affected by broader social and cultural constructs of cancer, is described in Chapter Eight.

The focus of hermeneutic phenomenology is on human experience (Van Manen 1990), hence Chapters Five to Eight focus on the patient-participants' lived experience. The nurse-participants' perspective on the emergent themes are integrated into the findings to enhance the depth of the phenomenological analysis.

Although the five existential themes are discussed separately (in different chapters), it is important to be aware that they form an 'intricate unity' (Van Manen 1990: 105) in the participants' lived experience and that the detachment of one dimension is somewhat artificial as during the lived experience of any phenomenon the corporeal, temporal, communal and spatial aspects are integrated.

### Writing

Writing up the analysis continued the process of data display, reduction and conclusion drawing and verification. Writing has been described as 'a form of cultivated thoughtfulness' (Van Manen 1990: 127). The process of writing has, in and of itself, contributed to the data analysis as it has prompted reflection and rethinking about the data. It has been especially useful as an aid to reflecting on what was silent or missing within the data (Van Manen 2006). The concept of missing data, which originated from the initial literature review, gradually became more evident during the process of analysis and re/writing until it became the overarching theme, as 'The

Missing Discourse' seemed to epitomise the silence about the effect of a family history of cancer within palliative care.

### Data Analysis: Researcher Perspective

As discussed in Chapter Three the study used a Heideggerian phenomenological methodology. This assumes that the research will take into account the involvement of the enquirer (Moran 2000). It allows the data to be analysed in the light of previous knowledge about the phenomena (Lopez and Willis 2004). Although the study was not attempting to ascertain whether participants had an inherited predisposition to cancer (rather to consider how a family history affected their care needs), it was motivated by the knowledge of inherited genetic predisposition to cancer. Hence it was appropriate to take this stance into account at all stages of the data analysis. This influenced how the data was reduced, displayed and the conclusions drawn (See Chapter Eleven).

### **Using the Research Literature**

As stated above (p52) an initial literature review was undertaken to help define the research question. In addition, reviewing the literature has been an ongoing feature of the research process. A key function of a literature review in qualitative research is concerned with the generalizability of findings (Silverman 2005). With this in mind the literature reviewed is considered alongside the findings presented. This shows how the findings relate to the cumulative body of knowledge about people with a family history of cancer (See Chapter Ten).

Different electronic databases were used to search for relevant literature as no one database provides comprehensive coverage of the literature (Cochrane Collaboration 2006). These included Medline, CINAHL, Web of Knowledge, Embase, and the British

Nursing Index. They were searched using Sackett et al (2000) schema for dissecting the research question in evidenced based medicine, which:

- Defines who the research is about: palliative care patients
- Defines the topic under investigation: inherited predisposition to cancer / familial cancer
- Defines the desired outcome: affect on care needs

This could also be described as a modified PICO (Patient, Intervention, Comparison and Outcome) search strategy (Gerrish and Lacey 2006). The search was limited to papers written after 1994, because 1994 was when the breast cancer gene BRCA 1 was discovered (Miki et al 1994). Although the idea of a family history of cancer long predates this, this discovery led to widespread debate about the ultimate impact of genetics on clinical medicine, and discussion about the implications for individuals at high risk of developing future disease (Holtzman and Marteau 2000, Conrade and Gabe 1999).

The comprehensive search strategy was helpful in ensuring that as many relevant studies as possible were identified and minimised the selection bias within the identified literature (Cochrane Collaboration 2006). It is noted throughout that there is a dearth of literature about the affect of a genetic predisposition to cancer on the care needs of the terminally ill. However, proving a lack of literature is difficult.

Consequently other search strategies were employed to ensure a comprehensive subject search. This included citation searching, hand-searching, use of the grey literature and using 'human contact sources'.

Citation searching is an efficient way of locating relevant literature (Greenhalgh 2006). It was a helpful strategy with regard to many of the emergent themes (for instance, communication about inherited susceptibility to cancer), but less useful with

regard to the main research question due to the lack of articles with appropriate citations.

Hand-searching of journals is a necessary adjunct to searching electronic databases because papers may be indexed in a way that makes it difficult to identify their relevance for a study (Cochrane Collaboration 2006). The available palliative care journals, sociological journals (Mortality; Omega; Death Studies) and nursing journals that focused on cancer care were hand-searched. This proved useful in identifying information that was relevant to this study.

The 'grey literature' was also searched for relevant information. This includes work of potentially high quality that is not published in peer reviewed sources (Beecroft et al 2006). DH and NICE documentation have informed this study. Lastly, contacting colleagues who have an interest in the research topic can be a fruitful way of locating relevant literature (Greenhalgh 2006). This was done, for instance, through professional networking at conferences. Despite these different search strategies only a limited literature was identified.

### Evaluating the Research Literature

Critical appraisal of research is necessary to ensure that it is trustworthy, valid, and applicable to the context where it is going to be used (Robson 2002, Booth 2006). Research is commonly appraised using a hierarchy of evidence. These hierarchies frequently evaluate quantitative research as having more consequence than qualitative research (Greenhalgh 2006, Cochrane Collaboration 2006). Nevertheless it has been argued that qualitative evidence is pertinent (when looking for evidence) to evaluate healthcare interventions, because of the need to address the impact of change from the perspective of the recipient and to take account of the broader environment in which the



change is situated (Evans 2003). It is argued that good and valid evidence about the appropriateness and feasibility of healthcare interventions can be obtained from interpretative studies because they present the patients' perspective and capture the subjective human experience which is often excluded from experimental work (Evans 2003).

In this study the paucity of appropriate and relevant evidence meant that no study was excluded because it used a methodology that is not generally considered to provide a strong evidence base for clinical practice. Expert opinion papers have been used. Expert opinion is frequently systematically biased towards the authors' opinion (Shekelle et al 1999), and can perpetuate bad practice (Greenhalgh 2006). Consequently it is regarded as having the lowest ranking within a hierarchy of evidence (Greenhalgh 2006, Evans 2003). Nevertheless it is used to implement change: notably with the use of expert patients in services development (Crawford et al 2002), and deciding when clinical guidelines need to be updated (Shekelle 2001).

The highest levels of evidence available to inform this study were information from a survey, and qualitative evidence (Evans 2003, Cochrane Collaboration 2006). This is perhaps unsurprising as qualitative methods are most appropriate for exploratory work about new phenomenon, like the emerging understanding of inherited genetic susceptibility to multifactorial disease, where many of the parameters are poorly understood, ill defined and difficult to control (Greenhalgh 2006). However, assessing quality in qualitative research is complex (Pope and Mays 2000), because qualitative research is dependant on the subjective experience of both researcher and researched (Greenhalgh 2006). Nevertheless much qualitative research (as this study) is based on the belief that there is an underlying reality which can be studied subjectively. From

this perspective, qualitative research is an attempt to represent reality rather than attain truth and it is possible to assess qualitative studies against agreed criteria (May and Pope 2000).

The Critical Appraisal Skills Programme (CASP) qualitative guidelines ([www.phru.nhs](http://www.phru.nhs) accessed 2006) were used to evaluate qualitative research studies. Although both the appropriateness of using criteria, and the nature of appropriate criteria are fiercely debated (Mays and Pope 2000, Booth 2006), these have been widely used in the evaluation of qualitative research in healthcare.

## **Conclusion**

This chapter has described the methodological processes adopted throughout study. It shows that the research has been systematically conducted within a specific context in a manner that was consistent with the underlying research philosophy. Further information about the strengths and weaknesses of these processes with regard to the study findings are described in Chapter Eleven.

## CHAPTER FIVE: THE MISSING BODIES

(The Lived Body)

*No man is an island entire unto itself ...every man is a piece of the continent a part of the main ... And therefore never send to know for whom the bell tolls: it tolls for thee*  
(John Donne 1572-1631)

### Introduction

The lived body (or corporeality) refers to the fact that we are present bodily in the world and that we meet and know others primarily through their physically embodied presence (Van Manen 1990). The experience of death, the annihilation of the physical body, was an inherent part of the experience of cancer for all the participants. All the patients were aware that they had advancing incurable disease with death being the anticipated outcome. Purposive sampling ensured that they had all been predeceased by at least one family member from cancer. This chapter is called ‘The Missing Bodies’ as it draws attention to the multiple ways that the participants’ families had been affected by previous deaths from cancer.

With inherited genetic predisposition to disease the family is the patient (Richards 1996). Hence this chapter considers the patients’ experience of cancer as an integral part of their family history of disease. Although this chapter equates to the physical dimension of care, it does so in an unconventional manner. Traditionally, palliative care has focused on the way cancer affects an individual physically (for instance, their symptoms and body image) but this chapter focuses on the physical experiences of cancer within the participants’ families.

This Chapter:

- 1) Introduces the Patient-Participants: This spotlights the individual patient’s experiences of cancer.

- 2) Reflects on their corporeal experiences: This draws attention to how the patients' experiences of cancer related to the corporeal experiences that are common in families with an inherited predisposition to cancer.
- 3) Presents a life stage perspective of their experiences: This highlights how the participants had been affected by their family history of cancer throughout their lives.

As stated in Chapter Three, hermeneutic phenomenology aims to go beyond the description of experiences to look for the meanings embedded within them (Lopez and Willis 2004). However, this chapter presents the situated bodily experiences (Crotty 1996) of the phenomena within which these meanings are embedded. It primarily addresses the first study aim: to describe the experience of a family history of cancer on patients within a palliative care setting. It underpins the subsequent chapters which focus on the meanings of these corporeal experiences for the participants.

### **Introduction to the Patient-Participants**

Each participant discussed previous occurrences of cancer within their family. A family tree was constructed for each participant (See Appendix Thirteen). A brief summary of the participants' experiences of cancer are given below.

- Anne had breast cancer. She was a sixty year old widow. Her sister, brother and niece had recently died from different cancers. A sixteen year old nephew had died from cancer approximately twenty years before. Her sole surviving sibling had been successfully treated for lung cancer as a young man.
- Beth had ovarian cancer eighteen years before her present diagnosis of bowel cancer. Her elderly father had also died from bowel cancer. She had three children.

- Claire had breast cancer. Her mother had died when she was five. Her sister had died from breast cancer aged twenty-eight and she had become legal guardian of her sister's children. Her elderly father also died from bowel cancer. She had four daughters.
- Diane was a married woman in her fifties. She had five children. Her maternal grandmother had died from cancer aged forty-three and her mother aged thirty-three. She had developed her first primary cancer whilst in her thirties and now had metastatic breast disease. Her niece, who was in her twenties, had recently been treated for breast cancer.
- Ezra's forty year old niece had died in the hospice; his nephew was also dying from terminal cancer in his forties. Although he had cancer he did not think that it was 'in his family' but in his 'sister-in-law's family' as she, like both her children had developed cancer and died whilst young. He had seen his grandparents die in childhood but was unsure of their diagnosis.
- Finlay was in his fifties. He had developed the same rare tumour, at a similar age, as his mother.
- Grace was forty-five. Her mother and sister had both died from cancer at a young age, whilst her father had died of cancer as an elderly man. Her brother was also living with cancer.
- Harry was the only participant who had been told that his disease was associated with a genetic predisposition to cancer by an oncologist. His father had died first in his family but two of his siblings had predeceased their mother: one leaving five dependant children. A third sibling had recently died whilst two were concurrently living with early stage disease. Harry was dying from his second primary cancer.

- Iain was fifty-five. He had lost his father and an older sister to cancer as a teenager. His mother and four other siblings had also died from cancer at a young age. A sixth sibling was concurrently receiving palliative care. Both Iain and his father had had multiple primary cancers.
- Jenny was in her fifties. She was the third of six sisters to develop ovarian and/or breast cancer. She also had a primary bowel tumour.
- Keith was sixty-four. His sister, niece and several in-laws had died in the hospice from cancer. He had lost both parents by the age of ten but was unaware of any details about their deaths.
- Leon was a seventy year old gentleman with prostate cancer. His only natural child had died predeceased him from ovarian cancer aged forty-two. He had adopted his granddaughter and two other children, one of whom had died aged forty-four (not from cancer). A brother had recently died from cancer.

These short summaries accentuate how diverse the lived experience of a family history of cancer can be for different individuals. For instance, Finlay only drew attention to his own experience in the context of his mother's experience of the same rare tumour at the same age, whilst Harry had been predeceased by seven first-degree relations. Each participant's experience gave a deeper appreciation of the way people could be affected by the phenomenon of a family history of cancer. Hence Anne, Diane, Jenny, and Leon all described the effect of the death of a young, female, family member in detail but from different perspectives: that of an aunt, child, sister and parent respectively.

## The Corporeal Experiences

All the participants were asked directly about previous occurrences of cancer within their family. Three corporeal experiences appeared to be important to the participants when they discussed this. These were:

- a) Multiple occurrences of cancer within the family
- b) Dying at a younger age than normal
- c) Living with multiple primary cancers

### Multiple Occurrences of Cancer within the Family

The impact of previous occurrences of cancer within the family was a major focus of the interviews. Table Five gives the details of the deaths and family cancers that were discussed in the interviews.

**Table 5: Multiple Occurrences of Cancer within the family**

Name	Significant Family Deaths from Cancer – 1 <sup>st</sup> & 2 <sup>nd</sup> degree relatives	Uncertain Diagnosis: Possibly Cancer?	Concurrent Cancers	Other deaths from Cancer	Other Significant Deaths Discussed (not cancer)	No. of 1 <sup>st</sup> /2 <sup>nd</sup> relatives with Cancer
Anne	Siblings (2) niece, nephew, uncle		Brother	Husband, niece-in law	Parents /grandparents	6
Beth	Father				Son	1
Claire	Father, sister	Mother		Son-in-law	Husband (RTA) Brother in law	2 (?3)
Diane	Mother, Grandmother		Father, Niece			4
Ezra	Grandparents Niece		nephew	niece's mother	Parents	2
Finlay	Mother					1
Grace	Mother, Father, Sister			Step mother		3
Harry	Mother, Father, Sister, Brothers (2)		Brothers (2)			7
Iain	Mother, Father, Siblings (5)		Sister			8
Jenny	Sister		Sister	Cousins Cousin's children		2
Keith	Sister, Niece	Mother, Father			Sister, Nieces (2)	2 (?4)
Leon	Daughter, Brother	Brother			Daughter, Brother	2 (?3)

\*Unsure of the diagnosis of grandparents

All the participants except Ezra had at least one first-degree blood relative with cancer, whilst Iain had the most with eight first-degree relatives with cancer. The number of relatives (bloodkin) with cancer in the participants' families (including the participants) ranged from between two to nine. The following two quotes show how varied participants lived experiences of cancer had been.

*My father: He had bowel cancer (Beth)*

*Out of nine brothers and sisters, which there was: there are four left, all the other ones have died of cancer. I had a sister die a few weeks ago of cancer ... I've got another sister, she is completely riddled with cancer (Iain)*

Many participants emphasised their awareness that multiple members of the family had cancer.

*It seems very unfair that you get so many people, especially as you have got me Dad, (three siblings named) and me who all have cancer of the stomach or bowel or something like that, and mother had this sort of skin cancer thing (Harry)*

*My niece ... my sister... my brother ... such a lot of it (Anne)*

*A lot of members of my family ... are ill ... from cancer (Jenny)*

Most of the people mentioned were first degree relatives. Five participants discussed the experiences of second-degree relatives. Jenny and Ezra were the only participants who discussed the experiences of more distant relations in detail.

### Dying at a Younger Age than is Usual

There was a huge variation in the amount of information given by patients about the deaths of different relatives. This variation perhaps reflected the different cancer experiences within different families, the different periods in the patient-participants' life histories in which the deaths occurred, and their relationship with the relative. However there was a consistent trend towards talking about deaths that occurred within the younger generation of the family. For example, five patient-participants discussed



the deaths of nieces and/or nephews whilst only one participant mentioned the deaths of aunts and uncles (see Table Five p93). The main reason for this trend appeared to be the increased emotional impact that these deaths had caused due to the young age at death.

*Because my sister didn't really have a life. ... She was so young ... So young, so young, but well, it is just unbelievable (Keith)*

*My mother, she was an old person, and she'd had her whole life. But with my sister, and my niece, and my husband, I just thought that it was very cruel (Anne)*

And because of the consequences of the deaths for the young-children within the family.

*She (Sister) had her family; a family of five... Five girls and she died (Harry)*

*She (Niece) was thirty six, she had two children (Keith)*

Eleven of the participants had been affected, some in multiple ways, by the affects of death occurring at a younger age than usual. Their relationship to these relatives who died young is shown in Table Six below.

**Table 6: Young Adult Death**

Patient Participant	Parental death in childhood (Age at death)	Sibling death or cancer when young adult	Death of child	Death or concurrent cancer of young relative
Anne		Brother (Lived)		Niece, Nephew
Beth			Son (Not Ca)	
Claire	Mother (5)	Sister		
Diane	Mother (11)			Niece (living)
Ezra				Niece, Nephew (living)
Finlay				
Grace	Mother (15) & Step-Mother	Sister		
Harry		Sister		
Iain	Father (14)	Sister		
Jenny				Cousins, Nieces & Nephews
Keith	Mother (4) & Father (10)	Sister (not ca)		Niece
Leon		Brother	2 Daughters (one cancer)	

For many of the participants the experience of young death interacted with the experience of multiple occurrences within the family:

*I lost my Mum to cancer when I was fifteen. My brother has got cancer. A lot of the family and relatives, like, have got cancer. My sister died when she was just forty-nine ... I'm forty-five. My mum died when she was fifty-five (Grace)*

Information about the meaning and impact of the young deaths of relatives from cancer for the participants is the primary focus of Chapter Six.

### Multiple Primary Cancers

Five participants stressed that they themselves had had two different experiences of cancer, some at different life stages. This is shown in Table Seven.

**Table 7: Lived Experiences of Multiple Primary Cancers**

Patient Participant	First Primary	Time between Primaries	Second Primary
Beth	Bowel	18 years	Ovarian
Diane	Rare Tumour	23 years	Breast
Harry	Bowel	5 years	Oesophageal
Iain	Stomach	22 years	Brain
Jenny	Bowel	3 years	Ovarian

*I've had cancer twice (Diane)*

*I'm going back, that was 18 years ago: I had got bowel cancer then (Beth)*

They frequently compared these two different experiences (see Chapter Seven).

Only one participant discussed a relative who had lived with multiple primary cancers.

*He (father) had cancer of the prostate for quite some time and then he got the other cancer and they couldn't do anything for him (Iain)*

It is not known whether the lack of information about this experience in the participants' relatives is a reflection of the relative rarity of multiple primary cancers or because participants emphasized how they had been affected by the deaths of relatives rather than their relatives' experiences of cancer.

### Reflection on Corporeal Experiences

One noteworthy aspect of the corporeal experiences that emerged from this study is that they are similar, but not identical to, the indicators of familial cancer that nurses are urged to consider when evaluating whether it is appropriate to refer a patient/family to specialist genetic services (See Table Two p17). Reflection on the differences between the way participants spoke about their family history of disease and the criteria in Table Two was revealing as it highlighted differences between the way the participants spoke about their cancer and the way healthcare professionals evaluate the risk of inherited predisposition to cancer.

The experience of ‘multiple experiences of cancer within the family’ included information that pertains to two of the criteria commonly used as indicators of an inherited predisposition to cancer within the family (Skirton and Patch 2002; Kirk 2004b): that there is cancer in several generations of the family, and that cancer occurs in the same or related parts of the body in different individuals within a family (Table Two p17). However it was not possible to ascertain whether the same or related cancers occurred within many of the participants’ families because:

- I. Several participants seemed to think that all cancer was the same disease rather than a word used to describe a family of diseases where abnormal cells proliferate (Kleinsmith 2006).

*A lot of the family and relatives, like, have got cancer (Grace)*

*That's when I found that I had cancer (Keith)*

- II. Confusion between metastatic and primary disease was commonly apparent in the interviews:

*In the meantime it had jumped from me prostate into me bones and I had the bone cancer as well (Leon)*

*Then my brother died of liver cancer, but it started off as bowel cancer  
(Anne)*

- III. Lack of knowledge about the type of cancers that other family members had experienced:

*A different sort to me, I think. They didn't put names to those things in those days (Diane)*

*It was a completely different cancer ... but I can't remember. Why do all the medical names have to be all the letters of the alphabet (Jenny)*

Many participants were unsure about the type of cancer from which their relatives had died.

- IV. Lack of clarity about their own disease:

*I forgot the name: it's on me records somewhere. It is some funny one  
(Iain)*

Ezra had deliberately chosen not be informed about his own disease. He knew that he had terminal cancer but not where it was in his body. He said his wife and daughter often spoke with the doctors about his illness but that he chose not to ask questions. He trusted his wife to make the right decisions.

- V. Communication difficulties within families meant that several participants had not been informed of their relative's diagnosis.

*I didn't even know she (sister) had died (Iain)*

*I said to my sister 'why didn't he (brother) tell people?' and she said 'I don't know' (Leon)*

This is discussed in detail in Chapter Six

- VI. Although all the participants discussed cancer in at least two generations of their families, only two participants gave details about three or more generations of their family history as required when completing a family pedigree.

The difficulty of relating the patients' descriptions of their lived-experience of a family history of cancer to the indicators of genetic predisposition emphasised that the participants were discussing their experiences as they saw them, with minimal or no reference to the discourse on cancer genetics. This suggests that participants were not primarily viewing their experiences from within a genetics paradigm. However the corporeal analysis emphasises that all the patient-participants had lived experience of an aspect of a family history of cancer that could be associated with inherited predisposition to disease.

The way that many participants emphasised the fact that relatives had died at a young age is related to, but not synonymous with the indicator that individuals with an inherited predisposition develop cancer at a younger age than is usual (Claus et al 1990). However, while participants rarely mentioned the age at which relatives had been diagnosed with cancer they commonly and spontaneously commented on their young age at death.

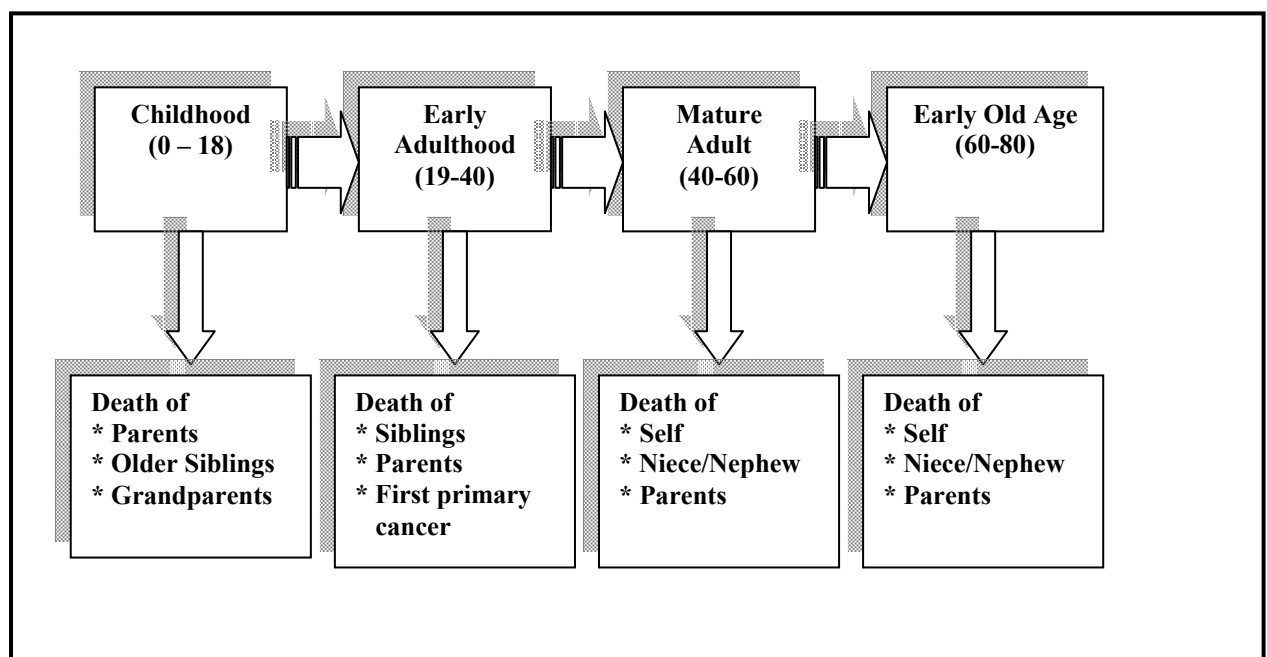
The precise meaning of the word 'younger' is ambiguous. For instance, when assessing for genetic predisposition different ages are used for different cancers. Hence the local regional genetic clinic suggests that for families with breast cancer referral may be appropriate when one relative develops the disease before aged forty or two before sixty. For colorectal cancer the given ages are forty-five for one relative and seventy for two relatives. The term 'earlier age than expected' is used for all other cancers ([www.bwhct.nhs](http://www.bwhct.nhs) accessed 12/2/2008). For the purposes of this study the word 'young' has been used to refer to any death where the participant emphasised the young age of the relative or when the participants' relatives were known to be fifty-five or under.

The corporeal analysis showed how diverse the physical consequences of a family history could be within different families. Despite this diversity, the fact that participants, when asked about previous occurrences of cancer within their family, focused on the deaths of first-degree relatives, alongside the experiences of young second degree relatives (for instance, nieces not aunts) suggest that they were salient features of the family history of cancer for participants.

### **The Life-Cycle Perspective**

The life-cycle analysis considers how the participants described being affected by cancer during the different stages of their lives. It was possible to synthesize the participants' experiences (as shown in Figure One) because of the consistent way the participants highlighted particular deaths as meaningful.

**Figure 1: The Lifecycle Perspective**



## Childhood

The deaths described as having the most impact on the participants during childhood were parental deaths. This was a significant event for each of the five participants who had this experience. Although parental death had different ramifications for individual participants, they all felt that it had impacted on their life history and their present experience of dying. Three participants had experienced the deaths of siblings during their childhood. Only one participant, Ezra, described the deaths of his grandparents during childhood as having any meaning or impact on his experience of living and dying with cancer.

## Deaths in Early Adulthood

The deaths that generated most comment from the participants about their early adult experiences of cancer were the deaths of siblings. Five participants had experienced this (See Table Six p95). These deaths had not only affected the participants emotionally because of their siblings' young age at death, they had also affected the participants' family structures, for instance, it altered the relationship with nieces and nephews (see p126). The death of parents continued to generate comment (but less information than parental deaths in childhood). Notably three participants had been multiple bereaved by early adulthood (see p127). No participant discussed the death of a grandparent in early adulthood. Three participants had been diagnosed with their first primary in early adulthood, causing them to consider their own mortality.

## Mature Adulthood

The deaths that appeared to have had the most impact on participants during their mature adult years were the deaths of the generation below them in the family. This

included adult children, nieces and nephews. The details of the deaths of more distant young relatives (for instance, Jenny's cousin's children) were also meaningful to the participants who emphasised their emotional impact. Several participants had also lost siblings and parents to cancer as mature adults. Many of the participants were themselves in this age group and were dealing with their own imminent deaths.

### Early Old Age

The type of deaths that impacted upon participants in early old age appeared to be similar to that which affected them in their mature adulthood. The main distinction appeared to be in the increasing number of siblings and other relatives that had pre-deceased them. Participants in this age group were also dealing with their own imminent deaths alongside concurrent illness within the family.

### Old Elderly

There were no participants in this age group. The only patient-participant (Harry) who had reached the average life expectancy in England of eighty-one for women or seventy-six years for men (<http://www.gad.gov.uk/life-tables> accessed 6/10/06) was, somewhat ironically, the sole participant who had been informed that he had an inherited genetic susceptibility to cancer.

### Reflection on the Life Cycle Perspective

Reflecting on the patient data from a life cycle perspective accentuated the fact, noted above, that participants' data emphasised deaths that occurred at a relatively young age, and that young deaths within the family have the potential to affect relatives, albeit in different ways, throughout their lifespan.

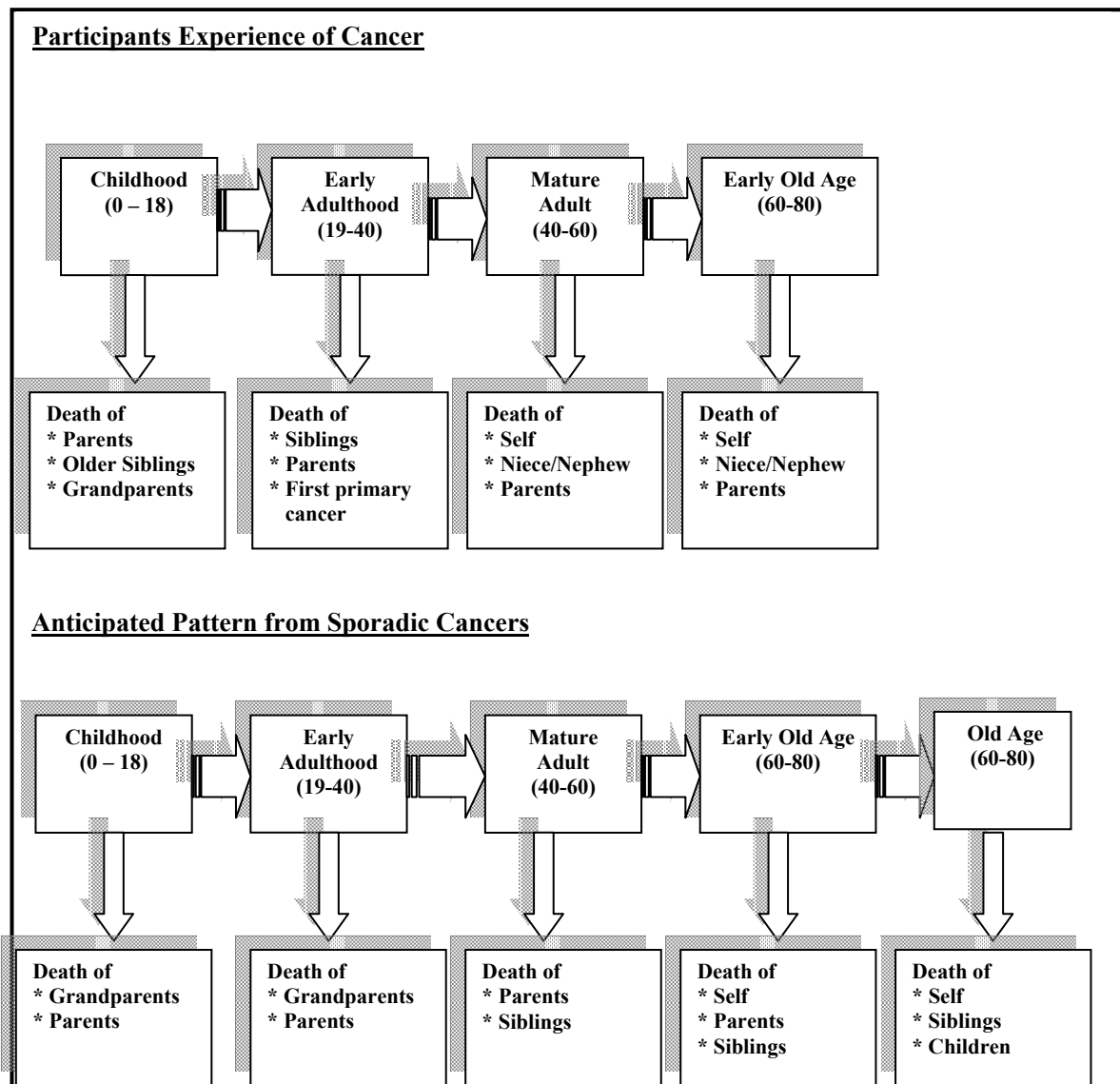


The pattern of deaths that affected the participants with a family history of cancer can be contrasted with the pattern of deaths that might be anticipated in a family with sporadic cancer. With sporadic cancer, children and young adults would be expected to experience the deaths of grandparents; mature adults, the death of parents, and early old age to be primarily affected by the deaths of parents and siblings with relatives who had died at a younger age than normal being a less common event. See Figure Two (below p104).

Investigation into how age at death affects the dying process can be found in the literature. This includes information about young adult dying (Grinyer 2002, Kyngas et al 2001, Grinyer 2007), death in young families (Willis et al 2001, Sheldon and Tribble 2004, MacPherson 2005, MacPherson and Emeleus 2007), mature adults deaths (Van der Molen 2000a,b) and the elderly (Esbensen et al 2004, Greco 2006). However this literature has a tendency to focus on the affect of individual deaths within families, not how they relate to other deaths within the family. With familial disease health care services are urged to consider the whole family as the patient (Richards 1996).

The comparison of the participants' experiences with the anticipated pattern from sporadic cancers (Figure Two p104) underlined the fact that patients with a family history of cancer may not only have experienced the deaths of more relatives but that these deaths can affect them throughout their lifespan.

**Figure 2: Comparison of participants' life cycle with the anticipated pattern from sporadic cancer**



The life-stage analysis may also help explain why half of the participants had another relative who was concurrently living with and/or dying from cancer. This is described as a rare event in the literature (Kissane and Bloch 2002). The participants were all mature adults or entering early old age. At this life-stage they are exposed to the sporadic cancers (that occur due to lifestyle, environmental and other factors) on both sides of the family. If the participants did have a genetic predisposition, it would be expected that other relatives who shared that predisposition might also develop cancer at a younger age than normal. Other family members, who were not predisposed

to cancer, would still be affected by sporadic cancers, (especially older relatives). Theoretically this would start to have its greatest impact around early old age: the age range of most of the study participants.

## **Discussion**

This chapter is called ‘The Missing Bodies’ to draw attention to the different ways that participants had been affected by previous deaths within their families. The introduction to the participants emphasised the diversity of events encompassed by the term ‘family history of cancer’. Although this study was not attempting to ascertain whether the participants had a genetic predisposition to cancer (rather to consider how their family history affected their care needs), consideration of the participants’ descriptions of the previous occurrences of cancer within their families called attention to several obstacles to the accurate assessment of risk within palliative care, as advocated by Kirk (2004a) and Lalloo et al (2000). Many participants were unsure about the details of their own disease and/or their relatives’ experiences of cancer. Moreover, the difficulty of obtaining an accurate family tree may be compounded by the fact that many specialist palliative services are independent and do not have automatic access to NHS patient notes.

The wide variety of experiences that constituted the family history of cancer for the participants drew attention to the need for sensitivity when this is being assessed. It may involve discussing meaningful and significant life experiences, as well as an intellectual assessment of the risk of genetic predisposition to cancer within a family. The fact that many participants had experienced multiple deaths, often of young relatives, stressed the importance of setting aside time for unhurried conversation, to allow patients to fully discuss how they had been affected by their family history.

Effective palliative care interventions require time, good communication skills and the development of a sense of connectedness with the patient (Twycross 2003, Fallowfield 2005). As the experiences associated with a family history of cancer alongside the potential for inherited disease may upset and distress patients and relatives (Mallet and Chekroud 2001), assessing the family history of cancer within palliative care would require similar skills.

Consideration of the findings from a life cycle perspective suggest that, the fact that individuals who have a family history of cancer commonly develop cancer and die at a younger age than usual, has the greatest and most consistent potential to affect participants throughout their lifespan. Deaths that occur at a younger age than normal can be inherently stressful to families due to the impact on children and the increased emotional response of families: even when they are considered outwith the genetic lens (MacPherson 2005, Willis et al 2001, Sheldon and Tribble 2004, MacPherson and Emeleus 2007). This suggests that an inherited predisposition to cancer may frequently be a pertinent issue in deaths which are already stressful for families due to the young age of the family member with incurable cancer.

The analysis of the corporeal experiences within the participants' families called attention to three physical experiences within the family that emerged as being a common concern to many participants. These were the multiple experiences of cancer within the family, the significance of the deaths of relatives at a young age and the experience of multiple primary cancers. These experiences are related to, but not synonymous with, indicators of an inherited predisposition to disease. The fact that these physical events normally have little significance within palliative care, underlines the way that the selection of variables considered to be significant changes depending upon the paradigm through which the world is viewed (Kuhn 1996). It underlines the

need to question basic principles during paradigmatic change (Kuhn 1996). It shows how fundamentally different the assessment of cancer within the family needs to be when consideration is given to the family history of disease as an integral part of care 'within a genetic paradigm'.

## **Conclusion**

Applying Van Manen's concept of the lived-body to Richards' (1996) insight that 'the patient is the family' with genetic disease clearly emphasises how different the physical assessment of care is 'outwith' and 'within' the genetics lens. Within the genetics paradigm the physical characteristics of the family history of cancer are vitally important, as a detailed and systematic investigation of the family pedigree can lead to the identification of individuals at risk of future disease. Outwith the genetics lens the physical attributes of relatives' cancer have a limited impact on the physical care of patients and their families. Nevertheless, previous occurrences of cancer do have the potential to affect the psychosocial aspects of care. This chapter contextualises the following chapters that focus more deeply but narrowly on how these corporeal experiences had affected the meaning of the participants' experience of cancer within a palliative care setting. The next chapter focuses on the effect on the lived-relationships within families and discusses how this affected the social dimensions of care.

## CHAPTER SIX: THE MISSING GENERATION

(The Lived Relationship)

*In every conceivable manner the family is link to our past, bridge to our future*  
(Alex Haley 1921-1992)

Relationality is the lived relationship we maintain with others in the interpersonal space that we share with them (Van Manen 1990). As we interact with others it allows us to develop and to transcend ourselves through shared communication and experience. Living in a particular family can inform how we see ourselves and are seen by others (Van Manen 1990). Genetic predisposition to disease is not only relational in the biological sense that altered genes are passed on in families. It is also relational in the psychosocial sense that it impacts on the way that families communicate and support one another (Koehly et al 2003). This relational analysis puts the patients at the centre of their families and considers how their family history of cancer has affected their relationship with their family. It draws attention to aspects of the patient experience that are important to the social dimensions of care.

The chapter opens with discussion of three themes that emerged from the patient data about their lived relationships.

- 1) *Family Communication*: This theme draws attention to the barriers to communication about the family history of cancer despite the participants' preference for open communication
- 2) *Family Cohesion*: This theme discusses the effect of death on the structure of the participants families
- 3) *Multiple deaths at a young age*: This theme considers how multiple bereavements in children and young adults can impact on family relationships

This is followed by the nurse-participant perspective on caring for young adult patients as the lived experience of young deaths emerged as a major component of each of the three themes discussed above.

- 4) *Caring for Adults who Die at a Younger Age than Anticipated*: This presents the aspect of caring for young adults and families that the nurse-participants found challenging

The chapter concludes with a discussion about how the altered lived relationships due to the family history of cancer may affect the social dimension of patients care.

## **Emerging Themes**

### ***Family Communication***

Knowledge of the way families communicate about familial disease is becoming increasingly important to healthcare professionals (Peterson and Bunton 2002). This is because an individual's knowledge of their family history can inform them about what hereditary diseases may be in their family (Walter and Emery 2005, Walter and Emery 2006) and because the fastest and most efficient way to trace people at high risk is when individuals pass on information about known risk to their relatives (Mester et al 2005, Wilson et al 2004).

All families have their own style of communication and vary in their communication patterns (Kenen et al 2004). The importance of family communication about cancer and death was stressed by all the participants. They frequently drew attention to the different ways that various family members had communicated about their disease. Perhaps unsurprisingly in a group of participants who volunteered to take part in a research interview, all but one of the participants were explicit about their belief that it was appropriate and helpful to speak openly about cancer.

*Talking is the thing that helps. It helps me the most (Anne)*

*And somebody will say; don't ask too many questions you might find out too much. And I've said, 'I'm not worried. Tell it to me now. Let me be ready' (Diane)*

*I don't believe in having secrets from anybody. If people come in here and they ask me about how I am they have been told I've got cancer (Harry)*

Several participants pointed out they how had benefited from the present culture of open communication about cancer. In the past cancer carried metaphorical overtones of punishment or curse and people were frequently secretive about cancer in their families (Sontag 1978). This attitude has changed with the media placing cancer high on the public agenda (Bunyon and Peterson 2005) and research that has encouraged open communication with patients (Maguire 1999). The participants felt they had benefitted from this in comparison to relatives who had died a generation ago when their family and social culture was that cancer was not openly discussed.

*My father never talked about it ... I don't think people talked about things so much in those days ... Because I've got people I can talk to and I do talk to ...so I don't think I worry about those things ... I think mainly the strength that I get is from the nurses I talked to, plus from my daughter particularly, and my husband (Beth)*

*You see in our days, in our younger days, you never talked about cancer. The big C was a (whispers) big secret (Leon)*

Several of the patients described particular incidents within their family where they felt that poor communication about cancer and death had adversely affected their family relationships. The difficulties that occurred within the family when secretive or obstructive communication patterns (Peterson 2005) were used by other family members had made some participants deliberately choose to communicate openly about their disease.

*My sister ... she knew at the end but she never told anybody ... It was a horrendous time. A horrible, horrible time.... When my other sister got hers (Diagnosis of cancer) I said 'look we had such a terrible time. Let's tell everybody you have got it: let's tell everybody ... So when I was diagnosed two*



*months later she said to me, 'we will tell everybody shall we' ... I tell everybody about it (Jenny)*

*He (Brother) had never let anybody really know that he had, that he was suffering and he just died. It was a shock to us him dying. Put it this way, me father and me sister, they were suffering over twelve months or eighteen months before they died and we knew eventually it would catch up with them (Harry)*

One participant also stated that poor family communication had affected their ability to assess their family history of cancer. Leon felt that this had contributed to delays in the diagnosis of his disease.

*When I came down with the prostate, he (Doctor) asked me if any other member of the family had it ... I said no. When me brother died, I found out that he had had prostate cancer and he had got over it: they had treated him ... but if anybody else in the family had it, I don't know (Leon)*

As he thought that his prostate cancer might have been treatable at an earlier stage he felt that the lack of family communication might have contributed to the fact that his illness was terminal. He also regretted that he had not had the opportunity to discuss his illness with his brother as he thought that this might have been beneficial and helpful for him.

*I couldn't discuss it with me brother, cause I didn't know nothing about it. He died before I was finally diagnosed (Leon)*

Only one participant did not advocate open communication. Although Grace participated in the study (hoping it would benefit others), she found the topic of cancer difficult and distasteful.

*I didn't want to talk about it ... We've all had cancer but we didn't talk about it. I mean it isn't nice (Grace)*

However, even she described how angry and frustrated she felt at her family's inability to discuss her illness and impending death with her.

*I told my family. At least I tried to talk to them about it but they don't seem to want to know. ... they try to change the subject. It makes me very, very, very angry (Grace)*

The perceived benefit of open communication was that it increased family cohesion and support:

*Since I've had this cancer, me two sisters ... They have made contact with me more (Iain)*

*And I think if you do tell people you've got the cancer ... I think people treat you, you know, a little bit better. They know you have got a serious illness and they make allowances (Leon)*

Family patterns of communication are challenged when the content of the communication is stressful (Panke and Ferrell 2005). Timely, sensitive, open and direct communication within families is essential to living well with familial disease (Rolland 2006). This study highlights the fact that the participants felt that open communication within families was equally important in the context of terminal disease. Although they consistently promoted open communication the research interviews highlighted two specific contexts that could make communication about a family history of cancer difficult. These were

- a) Communication in Families with Young Children
- b) Communication about Inherited Genetic Predisposition

#### Communication in Families with Young Children.

Ten of the patients described the deaths of relatives who had young children. The participants' family history of cancer meant that they had either experienced parental death as children, watched as siblings had tried and/or failed to communicate with their nieces or nephews or had to discuss their own cancer and impending death with young-children (see Table Six p95). Discussion of parental illness and death with young-children is complex (Forrest et al 2006, Holt 2006) and the difficulty of communicating with children was a recurring concern within this data.

Children want to know the truth and to be informed and involved in family events (Landry-Dattee & Delaigue-Cossett 2001). They may suspect that something is wrong before they are formally told about their parent's illness (Forrest et al 2006).

Participants who had experienced the death of family members during their childhood often clearly recalled their inability to instigate conversation or questions about familial illness as children.

*He (brother) died ... something to do with his blood when he was a child. That may have been a cancer, I just don't know. They never talked about it and in them days you didn't talk about cancer (Leon)*

*And we didn't ask questions where people do now: but you didn't ask questions when you were a child (Diane)*

Three of the five participants who had lost a parent in childhood were uncertain about the cause of their parents' death.

*My mum probably died of cancer, you know. I wouldn't know ... I don't know. I don't know, I don't know whether they would call it cancer then? Because, I was four, and it was sixty odd years ago. My father died, he was fifty-one, Eh, I don't remember, I was ten (Keith)*

One participant thought that he had been deliberately misinformed by his father who had not been able to discuss how serious his illness was with his children.

*He said to me it was a cyst on his stomach. But it was like this (indicates extent with his hands), it was out here. And it was cancer (Iain)*

Barnes et al (2000) found that the most common reason that parents gave for choosing to withhold information about their initial diagnosis of cancer was to avoid talking about cancer and death. Parents, even those who normally communicate well with their children, find it difficult to discuss their own, or their partners' approaching death (Landry-Dattee & Delaigue-Cossett 2001). This can be because the parent has real difficulty in accepting that they are in the terminal stage of illness and find it easier to talk about treatments. It can also be because they do not know what words to use to

explain their illness to their offspring or because of fears about their children's response and a desire to protect their children (Landry-Dattee & Delaigue-Cossett 2001).

Communication and the quality of family relationships are important for preventing adverse long term consequences (Hurd 1999). Difficulties in communicating about a parent's death appeared to persist, even for participants who thought that their family cohesion (see below) had been strengthened because of their childhood bereavement.

*We've only just started talking about it. ... My sister said to me, 'can you ask aunt (named) a few questions about mum? And I said 'Oh, well, I'll see', I don't like going down that road. But I'm going to see her next week, and I might bring it up, and sort of see what she says (Diane)*

The participants' parents' deaths happened at least a generation ago. However poor communication with children may still be widespread, for instance, one retrospective study of death in single parent families found that half of the children were not aware of the custody plans that had been arranged for them (Willis et al 2001). A study of bereaved children in Scotland (MacPherson 2005) also found that many children had not been told of their parent's impending death.

Telling a child that they have a terminal illness is one of the most difficult tasks that parents have to face (Brennan 2004, MacPherson 2005). The difficulties involved were stressed by those participants who were dying with young children, (and Diane who had been told she would die from her first primary cancer when her children were aged two to fifteen).

*About how long I've got to live. And how painfully, painfully it affects my children and my husband ... I'm worrying at the moment. I don't want to leave them here ... It scares me ... My only worry at the moment is my two kids (Grace)*

As noted above (p111) Grace did not feel she had been able to discuss her illness satisfactorily with any of her family. Nevertheless she had a plan to initiate conversation with the whole family (including her youngest child).

*I'm going to like, make a meeting ... Go for a meal, and I'll ask them what they want to do with me, when I die ... And thing like that. And I'm going to let them know what I want (Grace)*

Parents know their children better than any healthcare professional and it is good practice to support parents in their efforts to communicate with their children in the manner that they think will be most supportive for the children (Brennan 2004, MacPherson 2005). The participants accentuated the difficulty of doing this.

*They don't want to talk about it because I think they are frightened to talk about it. So, sometime I do mention a certain thing, which, especially my younger daughter, she just cannot accept. She just don't want to talk about it. Sometime, my older daughter she will ask me questions about it but the younger one ... (unable to continue) (Iain)*

Diane underscored her shock when she realised that her husband had told their children about her anticipated future death and how she had wanted to protect them from this knowledge until they were older.

*They were too young ... my husband talked to them and told them, 'I just heard from the doctor. I don't know how long mum will live'. I said, 'What! You can't say that to the kids' (Diane)*

Strong negative emotions in children are common in acute parental illness (Leedham and Meyorowitz 1999). These participants were very aware that their children were being affected by their impending death. They drew attention to the way that this had altered their relationships with their children. However the changes they described were very different in each case.

*And my third child ... He said 'I'm coming with you, mum' ... he meant he wanted to come with me when I die ... I mean, he was crying ... And then he turned out to be a horrible little trial. He was quite beyond me and he gave me a lot of problems at school and all that (Diane)*

Hence Diane emphasised how her son had wanted to be close to her as she was dying and had dealt with the knowledge of her illness in a way that meant that she had to focus on his needs as well as her own. This can be contrasted with Iain's experience

where he perceived that communication about his cancer had caused a distancing between himself and his teenage son.

*My lad at first was distanced to me: 'You're never going to die' like, or 'you are never sick'. And he is realising how bad I am because I am using the wheelchair and things. He is shocked I know that. He is like me; he is holding it back (Iain)*

This account of continuing to hold back suggests that Iain still felt distanced from his son, and was still holding back from discussing his advancing illness and impending death. This description highlighted that communication with children is an ongoing process (Brennan 2004) and that their understanding of the imminence of death can change with time, especially as the symptoms of the illness become more overt.

All three of the participants who were dying (or had faced death) with dependant children had lost a parent in childhood. Although they were conscious of this,

*I thought, 'Oh no, this is history repeating itself' (Diane)*

none of them made an overt comparison between their childhood experiences and their lived experience as a dying parent, but they all consistently emphasized the importance they placed on communicating with their children.

Participants who had seen other young-adult relatives die also regularly emphasised the importance of, and difficulties in, communicating with children. They emphasised the tragedy and sadness inherent in discussing parental cancer with children even when it done well by a family relative.

*She had a little boy a couple of years ago... It happened at Christmas time, just about Christmas time. She was telling her son then (Diane)*

They also described how difficult it had been to watch what had happened when relatives had not been able to talk about their cancer with their children before they died.

*She did not prepare her children. It was horrendous. She died on her son's birthday and we felt completely ... (participant can't find right word) (Jenny)*

Good family communication is important for children's psychological adjustment to illness (Leedham and Meyorowitz 1999, Hurd 1999). Non-verbal communication is also important (Brennan 2004). It is important to note that many participants, even those who said they found talking about cancer and death difficult, highlighted that they had good memories of other ways that they had been involved in caring for their dying relatives. This included good memories of being able to participate in the practical care of their relatives.

*And about me mum ... I used to make her drinks when she said she wanted them ... I liked doing that. She was asking me ... I would wait for her to wake ... I was there to help her (Grace)*

They also commented that that being present at their parent's death had been meaningful to them. Harry was nineteen when his father died:

*I was there when he died ... there was a friend of me mother's that was there and she went in to see him, and she said 'you had better come quick' and I went in ... and he was dying. He died of cancer; he died of that cancer (Harry)*

Conversely, Diane repeatedly commented how difficult she had found it that she had not been permitted to care for or visit her mother in hospital whilst she was dying:

*My mother... She was in hospital, she had an operation, she had treatment, and, it was too late when they got her sadly ... it was a traumatic time, she was taken away and I never saw her again. Well, I seen her, and my other sister seen her, but she was in the mortuary at the time. And, it wasn't a very nice picture to see of your mother, was it? (Diane)*

In this study, the communication issue that was most frequently highlighted as being complex and stressful was communication between a dying parent and their young children. This suggests that the fact that individuals from a family with an inherited predisposition to cancer are likely to die at a younger age than is usual (Risch 2001) can be a barrier to individuals who wish to know about their family history of cancer, due to the difficulties that parents have discussing their illness and impending death with children. The fact that three of the participants who had themselves lost a

parent as a young child had developed cancer whilst they had dependant children shows the potential for the repeated intergenerational experience of young adult death to make communication of an accurate family history of cancer very difficult and complex.

Only a small number of studies have specifically considered how the knowledge of inherited susceptibility to disease is passed on (Wilson et al 2004, Kenan et al 2004, Metcalfe et al 2008). However it is known that ‘barriers that may hinder disclosure to close or distant relatives include family rifts and tensions, divorce, separation and a desire not to cause alarm’ (Forrest-Kenan 2005: 210, Green et al 1997, Forrest et al 2003). This list is notable because it does not mention previous deaths within the family. This study suggests that death, especially the death of young adults with dependant children can be a barrier to communication about the family history of cancer.

#### Communication about Inherited Genetic Predisposition

The interview with Iain drew attention to the difficulties of introducing the topic of genetic predisposition with palliative patients. It revealed that he was concerned about his family history of cancer because he was very aware that a genetic predisposition to cancer could have real and significant implications for his children’s future. He was openly worried and emotionally distressed when he called attention to this:

*My only worry at the moment is my two kids. I was wondering if there was any way that they could be screened? To see if they have got cancer cells ...I just wondered if they had then whether they could get it treated at an early stage*  
(Iain)

As Iain became emotionally distressed whilst discussing these fears the tape recorder was switched off during part of the interview.

There is a consensus that children should not be tested for adult onset genetic illnesses because there are no known medical benefits for them in having this



information, and the psychosocial consequences of this information for children are not well understood (World Federation of Neurology 1990, Clarke and Flinter 1996). However, most children obtain their information about genetic disease within their family, from their interactions with adult family members (Tercyak et al 2001a,b). There has been little research into the best way to inform and counsel children about the possibility of inherited predisposition to disease (Miesfeldt et al 2003), although a meta-synthesis of this (limited) literature suggests many parents struggle with communicating about this topic with their children (Metcalf et al 2008). Nevertheless, there is evidence to suggest that children have concerns about ‘inheriting’ cancer. For instance, one study of young adult breast cancer survivors found that just over half of the participants said that their children had expressed concern about developing cancer. Participants were more likely to have discussed this risk with their older children. They felt that any concerns should be dealt with by parents rather than professionals (Miesfeldt et al 2003).

Iain later recommenced the interview to explain why he did not want to discuss the possibility of genetic predisposition with his young-children:

*They will find out that it is hereditary or whatever the word is and it will start them worrying. It might knock them out of all their studying, I'd rather they did their studying than thinking about cancer ... And to tell the kids, oh, you have got cancer, blah, blah, blah. You might get it in five years time or whatever; I'd rather them not know about it (Iain)*

Tercyak noted that ‘it is important that children know that a positive test result is not equivalent to a cancer diagnosis and should not be treated as such. Rather it is an indicator of risk’ (Tercyak 2002: 152). Iain’s statement ‘*And to tell the kids, oh, you have got cancer*’, suggests that he, himself, had not fully understood this distinction. It is a very subtle distinction that might be very difficult for children to make if the subject was first raised by a parent with advancing incurable disease. Iain’s

ambivalence about his children becoming aware of the potential for inherited disease was emphasised by his suggestion that he would raise the topic (by proxy), after death (sic):

*When I do die I'll have a word with my missus about getting them screened. In a couple of year's time: That way they are older and should understand more (Iain)*

The interview with Iain emphasises how difficult it could be to discuss an inherited predisposition to disease with dependant children in a palliative setting. It suggests that the attendant practical and ethical dilemmas that attend genetic counselling for parents and children (Hallowell et al 2003, Sherwin 2004) could be intensified in the context of advancing incurable disease. With Iain's permission and in his presence his concerns were disclosed to the hospice team after the interview. This was both to ensure that he was supported emotionally following his disclosure of his fears about his children's future, and to allow him more time to consider whether he wished to be referred to a specialist genetic service.

Although communication about inherited genetic predisposition within families is known to be complex (Green et al 1997, Forrest et al 2003, Foster et al 2004, Kenan et al 2003, Kenan et al 2004, Patenaude et al 2006), Iain's distress about the ramifications of family communication about the topic of inherited predisposition to cancer appeared to be exceptional in this study. Relatively little other information about the difficulty of communicating about the family history of cancer emerged.

Other participants had discussed their fears that cancer could be inherited with their adult-children:

*I do tell my kids now, be careful ...because it could be inherited, so be careful (Finlay)*

*I think it's hereditary ... and sometimes I say to my son, particularly, that you should have checkups (Beth)*

It is noteworthy that none of the participants who mentioned these discussions with their adult-children suggested that it had been a particularly difficult conversation, rather it appeared that they were a part of their ongoing efforts to ensure open communication about their disease within the family.

All the participants who mentioned discussing the potential for familial disease within the family had done so with the same intent, which was to encourage other family members to access preventative measures to reduce their relatives' chances of dying from the disease. Open communication about cancer risk was particularly important to the only participant who had been predeceased by an adult-child. He repeatedly linked the need for open communication about cancer to the potential for an inherited genetic predisposition to cancer.

*We talk about it ... I mean we have already had two; me daughter and myself. So we are not afraid to talk about cancer. I keep telling (grand/daughter) that she must do, because we don't know how her mother got her cancer so ... I keep telling her to have a check up, any lumps, you know what I mean. I tell her to have the smear and anything else. I say you are (Daughter named) daughter and if it is hereditary, you're liable to have it you know. So keep yourself checked (Leon)*

He wanted to ensure that his grand/daughter took advantage of cancer screening in case she developed cancer like her mother. He also talked about how the reality of losing two adult-children had meant that his surviving grand /children had to face the possibility that their deaths might also occur prematurely.

*So now the other two are reaching their forties. In fact they joke about it. They say 'well, what about us? One of us is going to die at forty six and the other at forty eight because there was two years between them (Leon)*

These pragmatic statements contrast with the earnest deliberation about communication within the family that has been documented in families who have made contact with genetic counselling services (Forrest et al 2003, Foster et al 2004, Kenan et al 2004, Gaff et al 2005). These studies document the importance that clients place

on informing other family members and the careful consideration that the participants had put into deciding whom to tell, when to tell and how to tell, including clients making concerted efforts to contact distant family members - even choosing intermediaries to discuss concerns about family members who might be at risk of future disease.

It has been shown that the knowledge of an inherited predisposition to cancer can invoke guilt (Lerman et al 1998, Mallet and Chekroud 2001), especially with regard to children (Van Oostrom 2007). However, none of the participants in this study expressed any guilt about the possibility of passing on their family history of disease. This might indicate that there is a genuine difference between having a family history of cancer and having a medically-endorsed inherited predisposition to cancer. This may be because genetic testing can reposition clients (Scott et al 2005) and alter the way they perceive illness within the family. These findings suggest that the psychosocial sequelae of a known genetic predisposition which frequently includes guilt (Mallet and Chekroud, Van Oostrom 2007) are not necessarily present in patients with a family history of cancer.

### ***Family Cohesion***

The family is a complex, relational social system that allows for the exchange of resources like information and support (Koehly et al 2003). There has been research into how the knowledge of an inherited genetic predisposition to cancer affects family cohesion (Koehly et al 2003, Edwards and Clarke 2004, McDaniel et al 2006, Van Oostrom et al 2007). Cohesion is defined as the sense of togetherness or emotional bonding within a family (Van Oostrom 2007) and reflects the level of commitment, help and support that families provide for one another (Edwards and Clarke 2004).

However these studies have not primarily focused on the effect of death within families with a family history of cancer.

The death of a parent in childhood had the most significant effect on family cohesion in this study. All five patients commented on the way these deaths had affected their experience of childhood. In particular they noted the emotional impact that it had had on them:

*That was the whole terrible experience: that was it really. I have got over it, but it took me a while. It took me a while to recover (Diane)*

*That seems tragic. You know, to think that it actually happened (Keith)*

But they also described profound changes in their experience of family life. Claire described how her mother's death when she was five had left her and her siblings open to physical and emotional abuse by her father. Her descriptions were graphic and were a major theme within the interview. The long lasting impact of this abuse was clearly illustrated when she described the scars on her back from the abuse as being much worse than the scars from her surgery. Diane also suggested that her childhood would be '*in the News of the World now*'. As she was the eldest daughter she took increased responsibility for caring for her seven siblings at aged eleven, and described, with humour, the lengths the family had gone to, to keep the authorities out and maintain family life.

*I'd go to school one week, my sister would go the other week, and she was nearly two years younger than me ... And we had no help, there was no help coming in. And we had this guy come in, I think he was a child officer or something, and I was in the house on my own. ... And he said 'who has done that?' (Cooked & Baked). And I said that I had; ... I was told not to say nothing (Diane)*

Nevertheless Diane felt that the experience of parental death had strengthened the relationship with her respective siblings and extended family:

*I was eleven and a half, the second eldest. The youngest one was one and a half, so we had to look after each other. You can imagine (Diane)*

This was also strongly emphasised by Keith who was the only participant who had lost both parents in childhood:

*I could have been an orphan, but you don't think about that because I wasn't. Because your brothers and sisters they just look after you ... We all lived together (Keith)*

These participants commented that this still affected their relationships with their family at the time of interview. They felt that their relationship with their siblings was closer because of the experience of parental death in childhood.

*So, I think I am quite close to all the family, like that being a mother, cause I used to, I brought them all up (Diane)*

*I think it makes me closer to the family I've got ... I've got a lovely family ... The family is there and so you have got to be there for them (Keith)*

This close relationship was demonstrated through practical support. For instance, Diane's family were arranging a last family holiday where she and all her siblings and children would visit her ailing father together (See p154). Keith's family had organised a rota where at least one sibling visited daily. These visits happened whether he was at home, hospital or an in-patient in the hospice.

*I've got such a wonderful family it is just a matter of who I speak to. I think I see one of my brothers or sisters once a day. Because they come and see me, I think they are worried about me (Keith)*

Hence two of the participants reported a strong family cohesiveness, which they directly associated with the way their family had pulled together when their parent died in childhood. These participants reported specific benefits from their families' ability to function together to support them. When cohesiveness in families is high it can buffer them through the dying process (Kissane and Bloch 2002).

In contrast, other participants' experiences illustrated how early parental death had caused or contributed to a breakdown in their family cohesion. Claire had left home as

soon as possible. She had had no contact with her mother's family since her mother died when she was five. She very much wanted to know what her mother looked like. She did not have any photographs and wondered if any of her grandchildren took after her mother. She was considering contacting the Salvation Army to see if they could trace any relatives on her mother's side so she could meet them before she died. Iain also felt that parental death had adversely affected his childhood.

*I never had much of an education. I'll be truthful, I've taught myself discipline and all, as I've got older (Iain)*

He also left home at an early age and simply said:

*And I'm not in touch with me family much (Iain).*

Poor family cohesion was also having an ongoing impact on these participants' present circumstances. Like Claire, Iain had tried to reconnect with his surviving siblings when he had been told that his cancer was incurable. Although his two surviving sisters had responded to his overtures he had been distressed by his sole surviving brother's response:

*Me one brother, I don't think I've seen him in about twenty years. And he said he thought I'd be dead by now already (Iain)*

Poor family cohesion is a factor that can predispose to higher levels of psychological distress and depression (Edwards and Clarke 2004).

The death of a parent is a non-normative life transition and the loss of both mothers (Shultz 2007) and fathers (East et al 2006) has been shown to have ongoing ramifications in adults. This study shows that the participants felt it was still affecting the support they received from their families. However, it was having very different impacts on different families. It is beyond the scope of this study to disentangle why parental deaths had such different effects on the cohesion of the different families.

The change in family cohesion was not restricted to participants who had lost a parent. It was also noted by other participants who had lost other young first degree adult relatives, especially the way that their contact with their relative's children had altered. Two participants had adopted their deceased relative's children. Claire, whose sister had died from breast cancer aged twenty-eight, had become the legal guardian for her nephews. She had maintained contact with them, spoke of them with affection and was proud of their on-going achievements. Leon had also adopted his grand/daughter. However two other participants commented on how much harder it had been to maintain contact with their deceased relative's children following their deaths. This was because of the difficulty in maintaining contact with relatives-in-law.

*We felt our hands were tied ... He (Brother-in-law) didn't even want us to know: her sisters and brothers and my mother particularly (Jenny)*

*She was 36, and she had a little boy ... so the little boy was with her husband; That was that (Anne)*

It is known that genetic information can be interrupted if a parent dies as aunts and uncles feel that they do not have the authority to talk to nieces and nephews about inherited disease (Forrest et al 2003, Wilson et al 2004), and lack of regular contact with relatives is a barrier both to communication about genetic risk and to knowledge about cancer in the family (Koehly et al 2003, Mesters et al 2005). Findings from this study suggest that the death of a parent may lead to relatives of the deceased parent feeling that even general continued contact with their in-laws is discouraged after death, never mind discussion about inherited susceptibility to disease.

In this study, the deaths of parents, siblings and children which occurred at a younger age than normal had the most consistent and significant impact on the participants' family structures. This is more likely to occur in families with a family history of cancer (Risch 2001). Foster et al (2002) suggest that the deaths of younger



relatives can be seen as suspicious and unnatural causing other family members to worry about the possibility of inherited cancer. Few of the participants in this study appeared to have made this link. Their concern was more focused on the emotional and practical impact that these early deaths had made on their experience of living and dying as part of a family with a family history of cancer. These deaths had both increased and decreased family cohesion. This in turn, has the potential to make contacting people about their potential risk of disease both easier and more difficult. It shows that in some families with a family history of cancer deaths of young adults will reduce family cohesion. This can limit their ability to know whether their family history of cancer indicates that they are at high risk of developing future disease (Koehly et al 2003, Mesters et al 2005).

### ***Multiple Deaths at a Young Age***

It was notable that for three of the participants who had experienced parental death the impact was compounded by other significant deaths whilst they were children or in their very early twenties.

*Unfortunately my eldest sister has died. ... I was probably twenty then. ..., twenty one ... She was in her thirties. She looked after us when my parents died (Keith)*

*I was fourteen when me dad died ... Then me sister died on me fifteenth birthday of cancer. ... She was in her late twenties (Iain)*

These sibling deaths generated much less data than the parental deaths and appeared to have had less effect on the participants' family structures or communication patterns. Nevertheless they emphasised the potential for repeated bereavements to affect individuals whilst they are still young where there is a family history of cancer.

Multiple bereavements within a short time space can have both immediate and long lasting consequences for children (Kaufman and Kaufman 2005, 2007).

Grace's story also demonstrated how the deaths of significant others who were not blood kin could also cause repeated bereavement. Her mother died from cancer when she was fifteen, her father had remarried but her step-mother then died of cancer when she was in her twenties. During the interview there was a 'slip of the tongue' when she said '*I was ten years with my mum: My step mum.*' (Grace). It led her to comment that she still missed and grieved for both her mothers. Very little has been written about grief and loss in children from reconstituted families although this is increasingly common in Britain due to remarriage after widowhood and divorce (Sheldon and Tribble 2004). There is a need to develop a better understanding of the complex emotional and familial issues involved (Sheldon and Tribble 2004).

The nurse interviews also raised the way multiple bereavements could affect the dying process and impede family coping. One nurse described how the death of a young adult was affected by the fact that her mother had died of the same cancer before her.

*We had a young girl who had cancer of the bowel, which was sort of in the family. Her mother had died of it, and she was only nineteen and she was dying of it. She ... couldn't cope and her father he just couldn't take it in. ... Because it had killed her mother, he couldn't cope with her having it. Her sister hadn't got it, but she had responsibilities to her in-laws and her own children... So it was just horrible and messy (NP8)*

In this scenario the complexities inherent in young-adult deaths (Grinyer 2002, 2007) were compounded by the stress of multiple occurrences of cancer within the family. The stress on the family system was such that it was faltering due to the complex emotional and social stressors that familial cancer had placed upon it. This meant that the family was not able to cohere into a unit to care for the dying. When the nurse reflected on the challenges that the scenario had made on the hospice team she said:

*What I learned was that there isn't an easy answer ... And the thought that she hadn't got her mother to look after her, to be tender with her. Her father couldn't look after her. Her sister was doing her best but was struggling ... It was lonely, it was horrible, it was ever so lonely (NP8)*

This scenario is similar to the life histories of the participants who had lost both a parent and sibling as young adults/children as given above. Interestingly, the nurse's strong emotional response to this scenario contrasts with the patient-participants' much briefer descriptions of their sibling deaths in childhood /early adulthood. The nurse's description of the scenario, (which had occurred several years before the interview) demonstrated how a family history of cancer can significantly affect the psychosocial and emotional care needs of patients and families receiving palliative care.

Although the nurse-participant stated that the cancer '*was sort of in the family*' and highlighted that her '*sister hadn't got it*' the nurse did not describe any specific actions that were taken due to the risk of heritable disease. However the complexity of the emotional and psychosocial distress emphasises the difficulties of leaving discussions about a family history of cancer until the dying phase. It also highlights the difficulties of finding a 'right' time, as the daughter was dying just as she left childhood, leaving a sister with young children possibly unaware of their future risk of disease. In addition, multiple losses can put great strain on families (Kissane and Bloch 2002). The nurse emphasised the emotional needs of the patient's father and sister. The comment '*that there isn't an easy answer*' underlined her understanding that caring for a family where a family history of cancer has made it difficult for them to cohere together provides complex challenges for the palliative care team.

### ***Caring for Adults who Die at a Younger Age than Anticipated***

The patient data presented above suggests the fact that individuals with a family history of cancer die at a younger age than normal had the greatest effect on the patient-participants' family relationships, and that this could be compounded by the potential for families to experience multiple losses of young family members. None of the nurses spontaneously associated the occurrence of cancer at a younger age than normal with familial cancer, however, when prompted, they all emphasised that the deaths of young adults frequently presented them with complex challenges; even without the issue of inherited disease.

The prime reason for this was because dying at a young age was perceived as untimely:

*I think, although it is almost ridiculous to say it, you associate death with old age don't you (NP6)*

Several of the nurses contrasted the acceptance of death in elderly patients with a feeling that life had not been fully lived when a younger patient was dying.

*Because there is an acceptance of death, when you are older, more so than there is when you are young (NP3)*

*Whereas mainly with the elderly... mainly they have said to me ... 'I have had a good life and I am ready to go' ... You don't really get that with the younger people or only with difficulty (NP8)*

Cancer and impending death can challenge any patient's self-identity, especially their body image, family, social and work relationships (Van Der Molen 2000a,b). All the nurses stated that dying young commonly increased these challenges, especially with regard to emotional and spiritual aspects of care.

*Physically I don't think it makes much difference at all but mentally, emotionally, spiritually it does make a big difference (NP5)*

*The younger deaths that I have seen here have all seemed more intense. ... I suppose there is more anger and more questions (NP2)*

*It is the shock element of somebody younger dying. And the questions, why me? Why has it happened to me when I have still got my life ahead of me. I think that is much more difficult to deal with, sometimes (NP4)*

Illness is known to interface differently at different stages in the family lifecycle (Brouwer-Dudokdewit et al 2002, Rolland 2006). The nurses highlighted the stress involved for all the family when a young adult was dying, including spouses:

*The younger husbands and wives ... I can see one husband looking at me, hoping that I will say that it will be OK. And I can't: and that is hard (NP3)*

And parents:

*The wrong order for the parents. It is the wrong way round. The parents say that it should be me not the child going first (NP1)*

But most participants described the main difference as being the care needs of children whose parents were dying:

*Also somebody younger is leaving behind dependants, people who depend on them, and that makes it all much more complicated (NP5)*

*There are obviously different support needs if you are trying to support children through that experience (NP3)*

*Particularly if there are children at home: they don't want to die at home ... they don't want the children to get distressed (NP8)*

When confronted with life threatening illness each family member has to redefine their expectations of themselves and their relationship with one another (Altschuler 2005). The way the patients' family interacted with one another was also said to influence the need for nursing care, with families of young patients who worked together as a unit being more able to support one another. When family members were unable to cohere together to care for the patient, nursing was more complex:

*They may have got previous partners and current partners, mothers and fathers who don't get on. And it is never just the patient; it is a whole melee of other things going on (NP8)*

*The way that each of the member of the family reacted was so different: It was a very, very exhausting assessment (NP1)*

Several nurses commented that they frequently accessed the resources of the multidisciplinary team when caring for young adults because of the inherent emotional stressors for patients and relatives.

*You can never really plan for how people are going to feel but basically I think you are in for a tumultuous time with young people who have got palliative cancer. ... You just know that you are in for a rough ride ... you have to have a team meeting and get the whole team on board because there is such a multiplicity of problems (NP8)*

This highlights the importance of adult palliative care nurses being able to refer to a multidisciplinary team. This is a necessary and appropriate resource within palliative care (Munroe 2005, Doyle 2005).

Lastly, young adult deaths were the one topic where it emerged that the nurse-participants themselves found their work stressful. All except one of the participants commented on how they personally found it more stressful to care for younger patients. The extra complexities of care included the difficulties of ‘being with’ (Andershed 2006, Johnson and Smith 2006) a young patient who did not want to die:

*And I think that it is much more difficult to be with someone who says ‘I want to live, I haven’t lived’; than to be with someone who says ‘when my children were little they did this and we did this’ who ... tells you their story than to be with someone who says I want to live my story (NP6)*

*I know we struggle as a team of nurses when we have had a young person in who is dying. Especially when he has a reason, every need to stay alive (NP3)*

They also drew attention to the way watching children loose a parent affected them.

*Very, different emotionally ... Especially if there are young children involved for them. Then we become really sad (NP6)*

*I think a lot more strain on us, I feel. It is always very difficult with the youngsters, all the way through. They deserve a lot more time that you haven’t always got to give (NP1)*

Children of dying parents may manifest significant distress (Beale et al 2004). They need age appropriate information to understand about cancer: its nature and meaning,

treatment and prospect of death (Laundry-Dattee and Delaigue-Cosset 2001, Kaufman and Kaufman 2005). Findings from this study suggest it was stressful for the nurses to provide this care. However it is known that palliative services that support children and surviving adults who commit to caring for children after a death can help those children's ongoing response to bereavement (Rolls and Payne 2003, Beale et al 2004).

The deaths of young-adults were the only scenario raised where the nurse-participants consistently stated that they felt stressed when providing care. This perhaps underlines how much young-adult death impacts upon the care needs of palliative care patients. As none of the nurses were aware that dying at a younger age than normal could be related to familial cancer, they were unable to comment on how these stresses might be compounded by inherited susceptibility to disease. However it does highlight that concerns about inherited disease are likely to occur in conjunction with care needs associated with deaths in young adults that are already challenging and stressful for nurses.

## **Discussion**

This chapter is called 'The Missing Generation' to draw attention to the way that previous deaths within the family (especially the deaths of young adults) had resulted in changes to family structures and difficulties in family communication about death, cancer and inherited disease. This chapter has described how the family history of cancer can affect family relationships, subtly altering the social dimensions of patients' care.

Traditionally, 'outwith the genetics paradigm' palliative services have concentrate on supporting people with strong societal, emotional and care-giving links to a patient (NICE 2004), rather than considering why patients have close supportive family

structures or less cohesive family structures. Poor family communication and cohesion can make it harder for family members to support one another during the dying process, whilst strong cohesion can enhance families' ability to support members through the dying process (Kissane and Bloch 2002). The nurse-participants found caring for families with poor cohesion more difficult as they tried to support the different needs of different family members

'Within the genetic paradigm' the issues of family cohesion and communication have an altered significance. They are important because family communication is the primary way that people learn about their risk of an inherited genetic predisposition to disease (Forrest et al 2003). Poor family cohesion and communication can prevent relatives learning about the cancer in their family, thus preventing them from accessing appropriate health prevention measures. The analysis of the participants' lived relationships suggests that it is the fact that individuals with a family history of cancer are more likely to develop cancer at a younger age than normal (Claus et al 1990) that has the greatest potential to impact on family cohesion and communication. Findings further suggest that the deaths of young adults with dependant children could be a significant barrier to communication about cancer within the family. Although all the patient-participants drew attention to the benefits of open communication, they consistently emphasised the difficulties of communication about dying with young children. Difficulties in family communication meant that several participants were unaware of the cause of deaths of first degree relatives.

Findings also suggested that the young age of children at death could be a major barrier to communication about inherited predisposition to cancer. Iain drew attention to how emotionally distressing it could be for parents to consider introducing the subject of inherited susceptibility to cancer when a family member had advancing



incurable disease. In this study all the participants who had discussed the potential for an inherited genetic predisposition to cancer with adult children had done so in the context of an overall decision to discuss cancer openly within their family. This suggests that discussion about inherited disease presupposes a willingness to discuss the illnesses and deaths of other family members in the context of death. This, in itself can be difficult for relatives of dying patients (Kissane 2008), and communication about death with children is difficult even for parents who prioritise open communication (Kaufman and Kaufman 2005).

The nurse-participants found caring for young adults stressful, especially if the patient involved, had young children. Although none of the nurse-participants were aware that developing cancer at a younger age than normal was associated with inherited cancers, they all felt that there were inherent stressors associated with caring for people who were dying at a younger age than normal. This suggests that the issue of inherited susceptibility to disease has the potential to complicate care scenarios that were inherently challenging for palliative care nurses.

Caring within the genetics paradigm would demand looking beyond the present practice. New challenges would include helping families communicate about the potential for an inherited genetic predisposition. This may be a particularly stressful issue for families with dependant children, although no similar distress was expressed when participants described discussing the issue with adult children. The genetic paradigm would similarly demand a change in perspective when assessing family support. It highlights the need not only to care for family members who are presently supporting patients, but also to question whether previous occurrences of cancer had affected the family cohesion and the support available. Similarly, caring within the genetics lens would accentuate the need to consider why individuals have undergone

multiple bereavements, alongside providing appropriate support. This could present new stressors to patients and nurses in a scenario which was already stressful for both participant groups.

## **Conclusion**

This chapter shows how the fact that individuals with a family history of cancer are more likely to develop cancer at a younger age than normal (Clause et al 1990) can have a significant affect on the lived-relationships within families. It shows how family communication and cohesion can be affected. It underscores the potential for individuals within the family to have been multiply bereaved at a young age. It drew attention to the way the nurse-participants described caring for young adults and families as being inherently stressful, especially if there were young-children involved. Finally, it calls attention to the way family communication and coherence are important issues within the genetics paradigm because they impact on individuals' knowledge about familial disease. (This is discussed further in Chapter Ten).

Although these issues affect the social dimensions of care, and primarily affect the lived relationship with other family members, they are obviously closely interwoven with the emotional care needs of patients. Hence it is important to consider how a family history of cancer can affect the emotional needs of patients. This is the focus of the next chapter.

## CHAPTER SEVEN: THE MISSING FUTURES

(Lived Time)

*I think the best physician is the one who has the providence to tell the patients according to his knowledge the present situation, what has happened before, and what is going to happen in the future (Hippocrates)*

### Introduction

The temporal experiences of past, present and future are the horizon of a person's lived experience of time (Van Manen 1990). The past influences the way that the present is experienced, both through vivid memories and near-forgotten experiences. The way that the past is conceptualised and interpreted may also change due to the pressures and influences of the present (Van Manen 1990). Similarly, expectations about what the future may hold influences the decisions and choices that are made in the present (Van Manen 1990). This chapter reflects on the temporal dimensions of the participants' experience of previous occurrences of cancer within their family and previous primary cancers. Reflection on the data from a temporal perspective revealed how the patient-participants' temporal focus changed when they discussed their experiences of cancer with regard to inherited susceptibility to disease.

This chapter addresses two issues. The first section draws attention to four temporal dimensions identified in relation to the experience of multiple occurrences of cancer in the family. These are

- Past to Present: '*Shadows in the Mind?*' This theme describes how patients were affected by previous occurrences of cancer within their family.
- The Lived Present: '*In it Together*': This theme looks at the effect of concurrent cancer within the Family
- Present to Future '*No Man is an Island*': This discusses the participants' perspectives on the future

- Present to Past: *'Re-evaluating the past'* This theme looks at how changed understanding of the aetiology of cancer made participants re-examine their past

This is followed by a discussion of how the potential for inherited disease altered the patients' concerns about the previous experiences of cancer within their family.

The second section of the chapter presents the temporal analysis of the information obtained about multiple primary cancers. Two temporal themes emerged from this data. They are

- Past separate from present *'The Past is Another Country'*
- Past continuous with present *'BOGOF: Buy One Get One Free'*

The analysis concludes with a discussion about how knowledge of an inherited predisposition to cancer has the potential to affect the way patients perceive the experience of multiple primary cancers.

Reflection on the data from a temporal perspective drew attention to the emotional dimensions of the care needs of the terminally ill with a family history of cancer. It underlined the way that participants' emotional needs changed depending on whether they were describing their family history of cancer in the light of the potential for inherited disease or were focusing on their own cancer journey.

## **Temporal Analysis of Multiple Occurrences of Cancer within the Family**

### ***Past to Present: Shadows in the Mind?***

This theme documents how past occurrences of cancer within the family affected the patients' present care needs. All the participants (patients and nurses) were directly asked about this. The patient responses fell into three categories: a) participants who felt it had no impact, b) participants who felt it had had a minor impact due to their increased awareness of death, and c) one atypical patient who described how the

previous occurrences had a major impact on their present needs. The nurses' responses also suggested a range of effects, which have been triangulated with, and presented alongside the patient data. This shows how the nurse and patient data corroborated each other and enhanced the understanding of the phenomena

#### a) No Impact

Almost half the patients did not think that previous occurrences of cancer within the family had affected their present care needs.

*No, I don't actually think so (Beth)*

*No ... it's not something I think about every day, you know (Diane)*

Claire elaborated on the reasons that she did not think that previous deaths had affected her needs; stating that she was five when her mother died so she could not remember any details, and that her sister had died in a different country so she had not been very involved whilst her sister was ill or dying. Other participants emphasised the lack of impact by indicating that they had not even discussed their relatives' experiences of cancer with hospice staff.

*I have never mentioned to anybody here that my mother had the same (Finlay)*

*Have you wanted to discuss what has happened in your family with the hospice? (I)*

*No (Grace)*

Many of the nurse-participants also thought that the family history of cancer had little impact on the care needs of palliative care patients. In fact, several nurses initially had difficulty answering the opening interview question: '*Can you tell me about a memorable scenario where a previous experience of cancer had a significant effect on the care needs of a patient?*' The immediate responses included:

*I can't think of a significant one at the moment ... It is not something that I can recall with patients at all (NP8)*

*Gosh, you mean have I actually nursed a patient here who has had another death in the family? (NP3)*

*Oh, I'll have to think: You mean when it had an effect on the actual patient? (NP9)*

Some of the nurses were themselves surprised and interested by this:

*One of the things that I have noticed ... is that often there is a family history. For that reason I am surprised that I can't think of more examples of people who are afraid and I think that is interesting (NP5)*

#### b) Minor Impact: Increased Awareness of the Dying Process

The most commonly perceived effect, which was emphasised by half of the patients and all the nurse participants, was that previous experiences of cancer in the family could increase the awareness of death and make the present threat of death more concrete.

*Really I think I could die because, well really, nobody has survived cancer. My sister, my niece, they didn't survive (Keith)*

*Yes it has changed things really. We realise, my wife and I, that cancer is a dangerous thing (Leon)*

*I watched them, you see, I watched them ... And I just sort of gradually, over the time, watched them deteriorate (Anne)*

Even Finlay, who had not discussed his family history of disease with hospice staff, reflected on how it had made the reality of death more imminent from the start of his own cancer journey.

*It has affected my own experience because, thinking about it, back to the hospital where my mother was. She died at the same hospital where I had the operation. She died there at the hospital (Finlay)*

A few patients also described how their increased awareness of the dying process had affected them. Three participants specifically stated that it had made it more

difficult for them to deny the fact that referral to palliative care services indicated that their disease was incurable.

*I've got a sister who died of cancer. She died in here, and her husband died of cancer. He died in here. My niece, she died in here ... I was apprehensive because my sister and two brother-in-laws died. And the illusion was that you go to (Hospice Named) and you don't come out (Keith)*

*The practice nurse ... and she offered to put me in touch with the Macmillan nurse or a hospice nurse. Well, I was horrified, because I thought hospice - death. So I said 'No, I don't want that. I don't want to go anywhere near' (Jenny)*

However, Jenny also drew attention to the way she felt her increased awareness of death due to her family history of cancer meant that she was more able to discuss her illness and death openly than other patients in the hospice. She had initially been surprised that other hospice patients had not accepted that they were dying from their cancer and had deliberately modified the way she talked with other patients.

*I tell everybody about it (Terminal Cancer) ... I mean, some of the ladies here have not accepted cancer. They died in the course (of aromatherapy) that we were having ..., I mean, one lady died in the three or four weeks. She hadn't accepted that she had cancer then. And so I thought you've got to be very careful about how you talk to people. I thought they are not all like you (Jenny)*

Iain also felt that his increased awareness of death had affected his response to cancer. He had been predeceased by six first degree relatives with cancer and felt this had helped prepared him for his own diagnosis, as his increased awareness had reduced the shock of his experience:

*I feel in no way shocked over what is happening to me (Iain)*

He said that his oncologist had been surprised by his acceptance that his treatment regime might not prove curative.

*He (Oncologist) said 'and if the treatment don't work, what then?' I said 'well if I've got any spare parts that are any good: flog them': I said 'because they are no good to me are they'. And he just looked at me. He said 'you've accepted it' and I said 'well we have all got to die sometime haven't we?'*

And although he was ambivalent about the way his awareness of death affected him, he did appear to think it made him accept the reality of his terminal prognosis.

*I'll be truthful love, if I die, I die ... Out of nine brothers and sisters, which there was, there are four left, all the other ones have died of cancer... And it upset me but I have got to accept it. We are all going to go and that is how I have accepted everything. I'll be upset for a couple of hours, or a day, but after that I'm OK. I've accepted it. (Iain)*

Iain's awareness that he was dying meant that he had actively tried to put his affairs in order to support his family.

*And I've accepted everything. I've even done me will. I've sorted out for me kid's education; the two youngest ones. ... if I die while still employed my two youngest are paid to go to university and everything (Iain)*

He also felt it had helped him to make an informed decision about his place of care.

*We (Iain and Nurse) got talking and we sorted things out: That when I am ready to die that I come in here. And she says I can. And I've arranged for (family named) to be here as well (Iain)*

Adapting to dying is one of the most monumental challenges that people have to cope with (Natanga 2003). Houghton states that his awareness that he was dying grew as his illness progressed and 'from remembering the experiences of others' (Houghton 2001: 74). Findings from the patient data suggest that one way the family history of cancer can affect patients is by increasing their awareness that they were dying. They appeared ambivalent about how this affected them: both highlighting the increased distress associated with referral to hospice, which they associated with death, whilst also drawing attention to the ways that they felt they were better able to discuss and plan for their dying process than people who had not had their experiences.

The nurses also drew attention to the way previous experiences of cancer in the family could increase the awareness of the dying process. They described both beneficial and detrimental effects from this: that it could be *a double edged thing*



(NP5). They noted that the increased knowledge base that previous experience of cancer could give patients could be advantageous. They thought it empowered patients to participate more fully and autonomously in treatment decisions.

*But I thought she was very much in control of what was happening to her ... What the future held. So in a way I felt that my role was less important in her case than others in a practical sense. Because so often when people are very ill, they need your input, your support, your knowledge whereas she ... with her history, was more in control and would kind of suggest to us, to me, what she wanted or what she thought would be appropriate (NP3)*

*They are probably coming in with a lot more knowledge as well, about the system and the situation, drugs and medication (NP7)*

*They kind of knew what to expect more ... They do because they know what kind of care they are likely to get. ... And they do take that care on board (NP6)*

*I have heard ... comments like 'oh well I know what to expect because my mum died of this' or 'my mum died of this too'. That kind of thing, so maybe that does help prepare them (NP9)*

It was also suggested that it allowed them to better anticipate, and therefore control, ongoing events in their dying trajectory.

*The good side is that if they have an anticipated idea of what to expect ... And it gives them some control over something which is uncontrollable (NP3)*

Two nurses specifically highlighted that they felt it enabled people to make a more informed choice about where they wanted to die.

*They have an awareness about what help is available ... And therefore they know it can be done at home, rather than have no experience and thinking that this person will have to go to hospice or hospital (NP1)*

Reviewing past experiences is one way that patients learn about cancer (Friesen et al 2002). The nurses suggested that patients' prior experience of disease could be a tool that enabled patients to maintain their independence and autonomy whilst utilising hospice care services. Maintaining independence and control has been shown to be important in preserving the quality of life of palliative care patients (Johnston and Smith 2006).

Despite this, the nurses regularly highlighted that previous experiences of cancer within a family were not invariably or automatically beneficial to patients, but rather depended on the specific characteristics of the deaths that they had witnessed. For instance, one nurse gave an example where an increased awareness of the dying trajectory had been helpful, then qualified her comment by saying that the experience was not generalisable.

*It can not be helpful as well, because it can make them more worried. Because then they can see the steps coming ... They can anticipate the nearness of death. Sometimes that is good and sometimes that is not good at all (NP6)*

Increased anxiety about the dying process was the most frequently discussed detrimental affect of previous experience of cancer within a family. This was thought to be especially prevalent when patients had previously witnessed a poorly managed death and anticipated that their own demise would follow a similar trajectory.

*It is maybe really unpleasant, how they have seen someone die. Then that is all they know. That is maybe the only person they have seen die. So they bring it up here (NP2)*

*And obviously they compare their experiences to what they experienced with their relatives. And they can't help but compare really, and often historical ones, that things once, 'oh me mum was in loads of pain', and often a long time ago and it can be hard to get them to realise that things have changed quite a lot (NP7)*

*This lady (Previous deceased relative) who had had breast cancer died with brain secondaries. And this patient remembered that and was very afraid and so was the family. And I remember that an awful lot of time had to be given up to be with that patient. To just let her talk (NP5)*

However, it was the manner of previous deaths that the nurses felt usually affected patients detrimentally rather than the experience of death *per se*.

*And they sort of expect, their expectations are really there: where that experience was. If they have had a bad experience in the past, they will come in here and expect the same or less (NP2)*

Fear and anxiety are known to be common occurrences in the dying (Parkes et al 1996, Vachon 2005a). The nurse-participant findings showed how previous experiences of cancer within the family may promote specific fears. This emphasised the fact that deaths do not occur in a vacuum and that the patients' own life history may not always be helpful to them as they die (Vachon 2005a). In addition the images that are held about death help shape individual responses to it (Brennan 2004) and previous experiences of badly managed deaths were thought by the nurses to present patients with images of their own death that caused them anxiety.

The nurses emphasised the need to spend time with patients and listen to these fears associated with previous deaths.

*You just need to be more sensitive to their needs. You obviously are more aware of their previous experience and you take more time explaining things. You try to be more approachable and more available. Get to know what their worries are and try to address it as best you can. You then go back to it to make sure everything is OK. That they understand and that they are getting what they want to get (NP2)*

*... obviously just listen and let them just get it off their chest. And you try and confirm that we will do our best to make sure that those symptoms don't occur if at all possible (NP8)*

*Whatever experiences they have had in the past, so you listen to them, you learn to listen. And listen to their culture: their way of seeing things, their way of doing things in the family, and how it affects them as well (NP7)*

Fear and anxiety are normal responses to danger and their causes need to be understood when caring for the dying (Parkes et al 1996). Assisting people to revise and reform their assumptions about the dying process can help them build new coping structures (Parkes et al 1996).

Good patient care is also known to be important to the relatives of dying patients (Andershed 2006). The nurses highlighted how information about the manner of previous deaths within the family could be important when assessing patients' anxieties

about particular aspects of the dying process. Findings from the nurse-participants suggested that the effect of previous poor care can continue and colour their relatives' own dying trajectories.

### c) Major Impact: Overwhelming Distress

There was one patient (Anne) whose entire dying process and present care needs appeared to be linked to the deaths of other family members from cancer. Although her life story did not appear inherently more calamitous than several others (see family trees: appendix 15), her description of her experiences differed from those of the other participants in several ways. These included:

- a) The recent suicide of a niece with cancer: '*She had a brain tumour, and she committed suicide*' (Anne). She spoke at length about this and how it had made her consider whether she should end her own life.
- b) Multiple recent family deaths that occurred within a short time span: her sister had died from leukaemia just five months before her niece's suicide. Her brother had since died from cancer.
- c) Emotional closeness to the deceased: Many of the people that she felt close to had predeceased her although she was just fifty-nine. Her husband had died (from a brain tumour). They had no children. Her sister, to whom she had felt particularly close, had died. '*In fact, all the people that I was close to are the ones who have died*' (Anne). Although she did have other living family she had never been close to them, did not know them well and felt little connection with them.

*They (remaining family) are fellow human beings .... But I don't feel any link ... I just feel totally detached from them (Anne)*

- d) Concurrent deaths of friends and in-laws: She had also had several friends and a nephew's wife with cancer. As she said:

*I just seem to have come across such a lot of it, all at the same time ... and I've never been to so many funerals: I was simply going from one funeral to another (Anne)*

These deaths had left her feeling extremely lonely, isolated and, in her own words, depressed, as she faced her own experience of cancer and death.

*I just felt as if I was the only person in the whole world, I just felt completely, totally isolated. I had nobody to turn to, I felt nobody would understand. Just totally alone (Anne)*

And also angry,

*It's left me angry really, more than anything (Anne)*

Anne frequently stated that she felt that the previous deaths of her family had made her present life meaningless.

*Because there have been times when I think this is just completely pointless ... if there was something for me to be around for (Anne)*

She regularly compared her own experience with her family's saying:

*I feel as if I'm in the same boat. A different cancer, but the same boat really (Anne)*

This had left her feeling guilty, wishing that she had treated her relatives differently whilst they were ill:

*And I think God I did it all wrong. The wrong things I did (Anne)*

Lastly, she struggled with how she was going to face her own death without the support of people she cared about:

*I just dread the future. I can't even bear the thought of the future at all: not in any way (Anne)*

Hence for Anne the whole dying process was deeply and detrimentally affected by her family history of cancer. She felt overwhelmed by the previous losses within the family and unable to surmount these concerns. Anne was the only participant who

mentioned that she was receiving support from several members of the multidisciplinary team with regard to her family history of cancer. This included support from various people including: a trained counsellor:

*I see a counsellor at the hospice (Anne)*

Alternative Therapists:

*I found the hospice, having alternative or complimentary therapies helpful ... just somebody touching me actually very helpful (Anne)*

Chaplaincy:

*... with religion. I've delved into Buddhism, and I've made lots of inquiries about lots of things (Anne)*

Anne did feel that the multidisciplinary hospice care was helpful to her:

*If I hadn't have had the hospice and their genuine care and concern, I think it would have just been unbearable, I don't know whether I would have committed suicide by now (Anne)*

Despite this, she still felt overwhelmed and isolated by the previous experiences of cancer within her family and continued:

*... in spite of all that, deep down, I still feel exactly the same, in fact, probably even more hopeless. Yes, more hopeless a way ... they (Hospice Staff) can't put themselves in your shoes. So, you can still feel completely isolated. I do, anyway (Anne)*

Several nurses also described scenarios where they felt that overwhelming distress associated with previous experience of cancer was a major component in a patients' care needs. None of the nurses felt that this was common, but they acknowledged that when it occurred it presented them with complex and memorable challenges. Hence the least experienced nurse to participate in this study, who had only worked in palliative care for a year, could only remember two scenarios where distress due to the family history of cancer had presented a major challenge to care.

*I think she was just so overwhelmed by grief; she was just so overwhelmed that she didn't know what. It was like she just couldn't take anymore. She was just absolutely broken ... So the main issue with her, it was almost, we had to help*

*her with this horrific amount of grief, it was grief you were dealing with before you could even look at the symptoms (NP9)*

In the second scenario, the overwhelming distress associated with the hospice because relatives had previously died there was strong enough to prevent a patient from returning to the hospice.

*There was an incident with a lady who didn't actually come to the hospice ... I actually met once as an outpatient... I just went down to bring her up from reception: and she was in a terrible state ... she was telling me about this awful history. I think the mum had recently died of breast cancer. I think she had another sister who was also affected ... it had a real impact on her (NP9)*

The assessment of emotional and psychological distress associated with the dying process involve distinguishing between the normal symptoms of adjustment to a terminal illness and the symptoms of a major depression requiring psychological referral (Vachon 2005a, Parkes et al 1996). In these scenarios the effect of a family history of cancer had meant that patients needed specialist care from the multidisciplinary team. Hence the nurse who described the scenarios above stated that her role providing appropriate care included:

*Making sure that all the team members are fully aware of what is happening (NP9)*

Anne's experience alongside the nurses' descriptions of overwhelming distress for some patients reiterated the appropriateness, and perhaps necessity, of having a multidisciplinary care team to support nursing care for some patients with a family history of cancer.

### Reflection on Past to Present

These findings showed that the previous occurrences of cancer in the family could have a wide range of effects on patients, from no perceived effect to overwhelming distress. There did not appear to be any straightforward relationship between the

strength of the effect and the number of relatives affected by cancer. Nor did there appear to be a correlation with the degree of relationship with the relatives who had died. For instance, Beth and Harry who been predeceased by one and seven first degree relatives respectively both reported no impact on care needs, whilst Iain and Jenny who had been predeceased by seven and one relatives respectively both drew attention to the way their increased awareness of death had affected their experience. Anne, who described her feelings of overwhelming distress, had been predeceased by five relatives (see Appendix Thirteen).

The level of impact on care needs did not appear to be related to diagnosis either. For instance, Anne, Diane and Jenny had breast or ovarian cancer. Nor did it appear to be associated with concern about heritable disease. Irrespective of the reasons for the different responses, juxtaposing Anne's lived experience with that of the other patient-participants' antithetical perceptions that previous occurrences of cancer within the family had no, or only a minor impact upon their care needs, emphasised how adeptly they were carrying their family history of cancer through their terminal phase.

It was notable, however, that Anne had lived through several experiences that are known to increase the risk of a complicated grief reaction following bereavement. These included multiple recent deaths, out of order death, and suicide (Parkes 1996, Parkes 1998). Similarly, individuals who have an absent or unhelpful family are more vulnerable to complex grief reactions (Parkes 1998, Stroebe et al 2006), and being recently predeceased by supportive family members had left this participant feeling alone and unsupported with terminal disease. Her description of her own lived-experience of dying suggest that it had become entangled in, and dominated by, a complex grief reaction due to her family history of cancer. It is beyond the remit of this study to consider the impact of grief upon the dying process, but Anne's experience,



alongside the scenarios described by the nurse-participants, does suggest that a family history of cancer can leave some patients particularly prone to the experience of living with advancing, incurable disease whilst dealing with a complex grief reaction due to the deaths of other family members. Anne's example showed that a family history of cancer could have a significant impact on care, even in patients who had no concerns about inherited disease.

The most commonly noted effect was an increased awareness of the dying process. Findings suggest this increased awareness had the potential to affect quality-of-life for patients, both equipping them with knowledge about the dying process and heightening the emotional significance of particular emotional milestones (like referral to hospice) associated with dying. Quality of life, like well-being, is a subjective experience (Brennan 2004). It includes attributes of self-awareness, coping and adjusting effectively with stress (Lin and Bauer-Wu 2003). Increased awareness of dying was perceived as being a 'two edged sword' with regard to patients' quality of life, both assisting patients to maintain their autonomy and/or increasing their anxieties about particular problematic aspects of dying.

Glaser and Straus's (1965) seminal work drew attention to the way open awareness of death improved communication with dying patients. They also stressed the importance of understanding dying trajectories (Glaser and Strauss 1968). They showed how recognition of familiar trajectories enabled staff to support patients and to plan care. Some of the patient-participants in this study had learnt about the dying process from their relative's experience. The nurse-participants suggested this knowledge can also help patients make autonomous decisions about their dying process. A recent literature review of psycho-spiritual well-being in patients with advanced cancer also supports the value that these participants placed on being aware

of their prognosis: ‘Although an awareness of having a limited time to live can evoke mixed emotions, this knowledge can facilitate coping and help patients live well in the present moment’ (Lin and Bauer-Wu 2003: 75). One study even found that awareness of dying was a better predictor of which patients would cope with dying at home than symptom load (Hinton 1994). Coping can be defined as ‘cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing’ (Lazarus and Folkman 1984: 141). These findings suggest that awareness of the dying trajectory due to the family history of cancer could similarly assist patients’ to cope with their dying process.

It is of interest that none of the patient outcomes, whether improved patient coping, specific fears or overwhelming distress, caused the nurses to focus on the family pedigree (see also Chapter Nine). This appeared to be because the previous history of cancer was not the loci of concern in any of the three potential outcomes. Firstly, increased coping was not a focus of care. As one nurse stated:

*I’m sure there are lots of positive effects but we tend to home in on the negative effects because that is where the patients tend to need the help (PP9)*

Secondly, when there were specific fears and anxieties related to a specific death the nursing objective was to reassure patients about those specific fears. Lastly, when there was overwhelming distress due to previous occurrences of cancer within the family the aim was to support the patients emotionally, using the diverse skills of the multidisciplinary team to deal with their distress rather than focus on the family history of cancer.

### ***The Lived Present: In it Together***

There was only one issue associated with the multiple occurrences of cancer within the participants' families that appeared to consistently impact on the patients' present lived experience. This was the support of other family members who had concurrent cancer. Six of the participants expressed concern about this, suggesting that it may be a common source of anxiety for patients with a family history of cancer. Although all of the participants were concerned about their relatives' health it was notable that they made a clear distinction between relatives who were dying from cancer,

*I've got another sister: she is completely riddled with cancer. There is nothing more they can do for her (Iain)*

*My dad ... he's been suffering from bladder cancer in the last year, so he's been in three times. But I don't think there's anything much more as they can do for him (Diane)*

and relatives who were living with cancer.

*I've got another brother, he is still alive, and he is still going reasonably well. He had a cancer in his bladder. So they managed to get part of it out and they cauterised the rest. He has to go for check-ups now and again but he has got a cancer of the bladder but he is still alive. (Harry)*

Some of the participants had found it supportive to have relatives with which to discuss their illness and treatment.

*My other sister had cancer ... So we had our radiotherapy together... So we were great support. We have always been great friends ... She is very supportive (Jenny)*

Whilst others reported being able to listen to, and support their relatives' concerns about hospital procedures:

*Then, me youngest brother, I was talking to him, a couple of days ago, well on Tuesday. And he told me, and he had told me before actually, that he had got to go to hospital as they had found some polyps in his bowel. He has been there and they have cauterised them ... and he said what a lot of courage I'd given him really (Harry)*

Social support has been shown to play an important role in the way patients cope and adjust to illness (Carmack-Taylor et al 2007) and these participants found consolation in both supporting and being supported by other relatives. Making contact with other dying relatives appeared to be especially important to patients. Iain had re-established contact with his sister who was also receiving palliative care (See p112). Diane had put considerable effort into overcoming obstacles to visiting her terminally ill father. She spoke about her plans with real hope and enthusiasm.

*We are all going on a trip together, two cottages. We are going to see dad. We are flying ...All of my kids are coming (Diane)*

Hope can be restored and maintained through the setting of realistic and achievable goals (Twycross 2003) and Diane hoped to be able to achieve her goal with the support of adult children. However she also expressed regret that she was not able to do more to support her elderly father. Ezra expected that his nephew would die before him. He was saddened because his lack of strength and mobility alongside transport problems prevented him from visiting and saying goodbye to his nephew who was an in-patient at a hospice in another city.

Being a relative of someone who has cancer and is dying is complex and people often need support to cope with the balance between the burden of caring and their capacity to care (Andershed 2006). This balance may be particularly difficult for relatives who have concurrent diagnosis of cancer, as they each depended on the support of other family members to enable them to, in turn, support each other. This suggests that assistance in enabling patients to support and communicate with other family members who have cancer, may be one effective way to care for patients with a family history of cancer.

It has been suggested that the burden of concurrent terminal illness within the family can exacerbate distress and anxiety to levels that warrant providing professional support to sustain the family's ability to cope (Kissane and Bloch 2002). However, none of the patient-participants appeared to display the intense grief that threatened the functioning of the family described by Kissane and Bloch (2002: 153). In contrast, in this study concurrent cancer was seen as an opportunity by the participants to offer as well as receive support. Nevertheless, being with and supporting other family members with cancer was an issue associated with their family history of cancer that these participants prioritised. It was a concern within their present lived experience.

### ***Present to Future: No man is an Island***

When the patients discussed their own future the data was dominated by the way they felt it was proscribed by their forthcoming death.

*Well, I'm going to die from it. I do realise that, yes, that that's the thing that will more than likely kill me (Beth)*

*I know what is going to happen to me medically ... I know I am going to die (Finlay)*

*They can help me, but they can't cure me. So I know that they can't cure me, so I suppose, what else is there to say? (Anne)*

The dominance of death as a future concern meant that future plans were proscribed and limited due to the possibility of death:

*You ask yourself what's going to happen, you want to know what's going to happen in the future, will I be alive? (Diane)*

*I made plans to go back to the West Indies but all that, I put that on hold (Finlay)*

Hence the participants drew attention to the way that their advancing disease process limited their future horizons.

It was notable, however, that when the topic of inherited genetic predisposition to cancer arose the participants drew attention to their fears that other family members, especially younger relatives, might develop cancer and die in the future. The depth of these fears was demonstrated by Jenny who stated that it was what had motivated her to participate in the study.

*If it is on the cards that one of my nephews and nieces, or one of my great nephews and nieces are going to have cancer, then I want to do everything possible to help the future. I will do anything; I will talk to anybody (Jenny)*

It was notable that all the concerns about the possibility of other family members developing cancer in the future were raised in the context of cancer being associated with an inherited genetic predisposition to cancer. Concerns about familial cancer were widespread in this study and existed in participants who:

- a) Did not think that their own cancer was associated with an inherited genetic predisposition to cancer.
- b) Had been informed by the regional clinical genetics unit that their family history of cancer did not indicate a high risk of genetic predisposition..
- c) Had not discussed these concerns before.

Each of these aspects is discussed in more detail below.

a) It was notable that several patients expressed fears that their children and grandchildren might be at increased risk of developing cancer due to their family history of disease, even when they excluded or had reservations about their own (or their deceased relatives') illness being associated with a genetic cause. For instance, when asked about the causes of her own cancer, Beth clearly linked the aetiology of her own disease with the stress that followed the (non cancer) death of one of her children.

*I lost one son nearly 9 years ago, I was wondering if it was the shock of that. I don't know. I'm just presuming ... They do say shock can bring it on ... I haven't really thought about the causes, except for the shock (Beth)*

However, (about half an hour later), when she was talking about whether she discussed her illness with other family members she said:

*I think it's hereditary, because I had it, and my father had it. And I sometimes say to my son, particularly, that you should have checkups. ... That he ought to have checkups (Beth)*

Similarly Finlay attributed his own cancer to a Western diet full of additives.

*There is less of this cancer thing in the West Indies, cause people eat natural stuff, natural food ... and they cannot afford to have junk food because they don't know where their next meal is coming from ... living in a fast country, a country like England you don't have the time to cook sometimes, so you just eat anything (Finlay)*

But he too, later mentioned that he was aware that cancer could be associated with an inherited predisposition and had warned his adult-children about this.

*I do tell my kids now, be careful ...because it could be inherited: so be careful (Finlay)*

Leon was aware that genetics could have a powerful and significant impact on health.

*Because your genes rule your life don't they? ... They build you to what you are: whether you are going to be ill, seriously ill, or whether you are going to live till you are one hundred. It's your genes ... that progress your life (Leon)*

Nevertheless he was also aware of the potential lifestyle factors that might have contributed to cancer within his family.

*Dad was an avid smoker ... then as we grew older me brothers started smoking. So you was living in an atmosphere of smoke ... I'd walk into the house and you could cut the air with a knife with smoke ... And then when I had the family they all smoked (Leon)*

He attributed his daughter's cancer to iatrogenic causes.

*We swear to this day that if she hadn't have had that treatment (IVF) she would have been here today. Everybody says (Leon)*

Hence he was ambivalent about the role of inherited genetic susceptibility as a cause of cancer within his family:

*We can't say whether cancer runs in the family or not (Leon)*

Despite his ambivalence, his awareness that cancer could be inherited had caused to him to raise the issue with his grand/daughter because he was anxious that his grand/daughter accessed all and any screening checks and received treatment as soon as possible.

*Because we don't know how her mother got her cancer so... So I keep telling her to have a check up ... I tell her to have the smear and anything else. I say you are her daughter and if it is hereditary, you're liable to have it you know (Leon)*

Hence, even the awareness that cancer could be genetic appeared to lead to increased fears for relatives, even when participants were unclear or hesitant about the involvement of inheritance in the aetiology of their own disease.

It is known that the death, or anticipated death, of a relative can enhance fears of susceptibility to cancer in the relatives of cancer patients (Saunders et al 2003). This did not appear to be the case in this study (although the study design means it is impossible to say whether the patients' concerns were enhanced by the participants' advanced disease) but it does show that concerns for the future health of other family members due to fears about genetic predisposition are not only present in palliative care patients who believe their own disease is due to an inherited susceptibility to cancer.

Participants in this study had discussed these fears with their relatives. Hollowell (1999) found that at-risk relatives had been prompted to attend for genetic counselling following discussion of risk of future disease with dying relatives. Consequently, these conversations have the potential to impact on the actions of the participants' relatives.



Despite these reported conversations with relatives, none of the participants above had discussed their concerns for their children with healthcare professionals.

b) There was one participant who had previously been referred to the regional clinical genetics unit for assessment of her family history of cancer by her GP.

*That was Dr P. that suggested it. Because I asked him and he said it would be a good idea (Diane)*

Diane was unsure about where she had first heard of the possibility that cancer could be familial but thought that it might have been a magazine or a radio programme. She had seen a link with her own family history of cancer:

*My grandmother had it, my mother's mother and my mother (Diane)*

The young age that individuals within her family had developed cancer had also alerted her to the potential of an inherited susceptibility: her grandmother died of cancer aged forty-two and her mother aged thirty-three. She had developed her first primary cancer aged thirty-six and twenty-three years later had developed breast cancer. She had approached her GP about genetic counselling following her diagnosis with breast cancer because of concerns for her daughters' future:

*I've got five kids and my sister ... and I'll be very upset if anything happens to them ... I would be very distraught, if anything happened to them (Diane)*

This is a common reason for individuals who already have cancer to request genetic counselling (Bonadona 2002, Hallowell et al 2004). In Diane's case the GP had referred the family to the regional specialist genetic clinic. Although she had initiated the process of referral she had not attended the clinic due to poor health. Her daughters had, however, attended the consultation with the geneticist.

*They spoke to the doctor and got all the information, and they said it was just unfortunate, and that it mightn't happen to the girls at all: which is a relief (Diane)*

This had allowed her to focus on her own illness but it had not fully reassured her about her daughters' future health:

*They are all fine at the moment. I just hope the girls watch themselves. Just in case it makes a repeat. But, according to the gene clinic I was just unfortunate (Diane)*

And she continued to encourage them to be alert for the early stages of disease:

*I say look after yourself, keep on feeling around (demonstrated breast examination), if you feel anything, there, tell someone. I would be very distraught, if anything happened to them, you know (Diane)*

Hence the referral to the regional clinical genetics unit had been initiated by the patient after she had re-evaluated her family history of cancer in the light of new information about the aetiology of cancer. The reassurance the family had been given had helped her focus on her own needs and had reduced her fears about her daughters' future. Nevertheless she had not stopped worrying about her daughters' future health, perhaps because her lived experience of her mother dying in her childhood and the awareness that her grandmother had also died as a young woman from cancer overrode the reassurance from the geneticist. She continued to think that her cancer was due to a 'rogue gene' (Diane) but did not think that this in anyway affected the care that she needed from the hospice.

It had been suggested that relatives experience an increased perception of risk around the time of bereavement (Rees et al 2001, Sanders et al 2003). For this patient, concerns about the implications of her disease seemed to be held in balance despite disease progression: she had obtained some reassurance from knowing that her adult-daughters were not thought to be at increased risk of disease but this was held in tension because of her family history of cancer and her deteriorating condition. That is, the historical and present reality of the disease had mitigated against the reassurance

received (Agincourt-Canning 2001). Hence she was still dying with fears for her adult-children's future.

c) The research interviews also revealed one participant (Iain) who had not previously expressed his fears about inherited disease with healthcare professionals. He had not previously disclosed his full family history of cancer to a healthcare professional as he had not maintained close contact with his siblings following the deaths of his parents. He had, however, been predeceased by seven first degree relatives from cancer and had a sister who was concurrently dying from cancer. The interview, especially the questions about previous occurrences of cancer within the family, made Iain re/consider whether his family history of cancer might be related to an inherited genetic predisposition to cancer.

*No, and I'm just thinking out of the eleven of us there are four left. So I'm wondering if it is inherited (Iain)*

He had perhaps considered whether his cancer might have been associated with an inherited predisposition to cancer before this because he then said:

*Because I've got to find out; to see whether it is inherited. But others say it is not (Iain)*

However he had not discussed whether his family history might be associated with an inherited predisposition with the his medical team or hospice staff:

*Have you asked your doctors about it? (I)*  
*No, I've just been thinking about it now ... I don't think I'm scared to ask (Iain)*

As discussed above (see p118), Iain became distressed when considering the implications of his disease for his children and chose to initiate a discussion with the medical team about the potential for genetic disease. Iain died three weeks following the interview. This indicated that without the research study he might not have had the opportunity to explore his concerns about his family history of cancer and its

implications for his family. Although this conversation provoked distress the value of open awareness about difficult and emotive aspects of terminal disease is one of the foundations of palliative care (Searle et al 1997, Glaser and Straus 1965).

### Reflection on Present to Future

There was a consistent and notable change in the participants' fears about the future when the topic of inherited disease was raised. Outwith the genetic lens they focused on their own forthcoming experience of death and their limited future. However in the context of genetic disease the focus of their concern was on the implications of their illness for other family members. These concerns were pervasive and meaningful, even to participants who did not perceive their own disease to be due to an inherited susceptibility to cancer

Consequently, caring for patients with a family history of cancer needs to encompass an appropriate response to patients who are worried about whether the cancer in their family might have implications for their relatives' future health. Nursing care relies on both a sound knowledge base and practical expertise (Benner 1984). Nurses need not only to be able to identify patients who might benefit from genetics services but also the ability to communicate this information appropriately with concerned patients. These are both core genetic competencies for nurses. (See Table One p16).

### ***Present to Past: Re-Evaluation of the past***

There was some evidence that patients were re-evaluating their past family history in the light of new information about cancer genetics. For instance, Harry had reconsidered the family history of disease after a discussion with the oncologist.

*It was one of the registrars ... he says 'has there been cancer in your family? And it set me thinking then ... He was talking about the genes. It's in the genes he said ... I've got an idea, I think that somehow it is genetic (Harry)*

Hence for Harry the awareness that cancer could be associated with inherited genetic factors had caused him to reconsider the origin of his own and his family's disease.

*Well I'm wondering myself sometimes whether it is a gene that goes through the family that causes this ... I don't know. It seems very unfair that you get people, especially as you have got me Dad, (Three siblings named) and me who all have cancer of the stomach or bowel or something like that (Harry)*

He did not know about the experience of more distant relatives but had pondered whether investigating his family's history of disease would be helpful:

*I keep thinking is it there in the family? I don't know whether you can go back and see if it is in the (surname) clan ... But it is in my immediate family (Harry)*

For Harry the re-evaluation of the cause of his family history of cancer did not appear to cause any new fears, perhaps because he did not have children and many of his siblings had predeceased him.

Diane (see p159) had similarly re-evaluated her family history after reading about a family with 'the breast cancer gene'. Although she could not now remember where she had first heard about this:

*I don't know, I'd read about it somewhere (Diane)*

The media are a crucial source of information about health and illness and 'soft', human interest, first person accounts about families with the BRCA genes have been shown to have engaged peoples imagination and understanding of genetic predisposition to cancer (Henderson and Kitzinger 1999). This and a direct conversation with an oncologist were the two sources of information that had made participants seriously re-evaluate their family history of disease in this study.

### ***Reflection on the Temporal Analysis of Multiple Occurrences of Cancer in the Family***

The temporal analysis of the experience of multiple occurrences of cancer within the family shows how the change to a genetic paradigm, where the potential for cancer to be inherited is endorsed, can affect the emotional needs of palliative care patients, as it affects the meaning and significance of past experiences of cancer within the family.

Outwith the genetic lens past multiple occurrences of cancer within the family encompassed a range of effects on participants' present lived experience.

- Previous occurrences of cancer had a range of effects on the participants: many stated that they had very little or no impact on their present care needs. Others described how it had subtly increased their awareness that they were dying and informed them about the dying process. Only one participant, Anne, stated that they had a major impact on her present experience. (See P146).
- All the participants who had relatives who were concurrently living with cancer wanted to support them and/or appreciated being supported by them.
- Outwith the genetics lens the participants' future concerns focused on their own forthcoming deaths and how their present lived experience was proscribed by their approaching deaths.

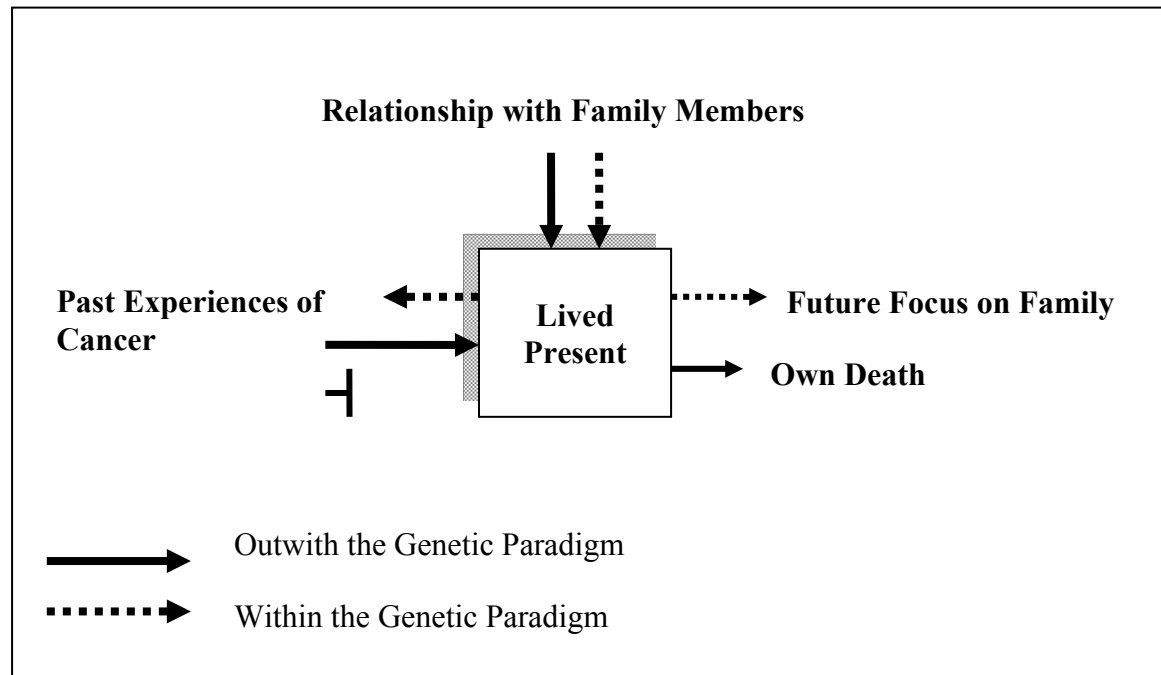
All of these effects appeared to continue within the genetic lens. However the introduction of the concept of genetic inheritance also added two new temporal dimensions to the participants' experience.

- The participants' concerns about the future changed from a concern about their own death to concern about whether other family members would develop cancer in the future.

- Some participants had re-evaluated their family history in light of their knowledge about genetics.

This change is illustrated diagrammatically in Figure Three below.

**Figure 3: Diagrammatic Model of Temporal Analysis**



The number of participants who expressed concern about the implications of their family history of disease for future generations showed how pertinent concerns about genetic susceptibility to cancer can be within the palliative care setting. Concerns about the implications of genetic predisposition to cancer for their (adult) children's future were widespread and relevant, even in patients who did not think that their own cancer was associated with inherited disease, as well as a patients who had been reassured by the regional clinical genetics unit that her family history of disease did not indicate that her children were at high risk of developing disease.

When evaluating the temporal analysis of the data it is important to remember that the research interview primarily focused on the impact of the past on the present. To prevent the research interviews provoking undue distress about the participants'

forthcoming death the interview proforma was deliberately constructed around the past and the present (as opposed to their future and anticipated death). The research ethics committee specifically refused permission for the researcher to ask about the impact of cancer on the younger generation/children in the family. Hence all the information about participants' concerns for the future was spontaneously given by the participants without prompting. This emphasises its importance to them.

### **Temporal Analysis of Multiple Primary Cancers**

Another indicator that there may be an inherited genetic predisposition to cancer within a family is that individuals within that family are affected by multiple primary cancers (Ford et al 1998, Aarnio et al 1995). Although five participants spontaneously talked about the experience of having had a previous primary cancer, only one, Harry, associated his experiences of cancer with an inherited susceptibility to cancer.

### ***Past Separate from Present: The Past is Another Country***

The four patients who did not associate their experience of multiple primary cancers with genetic disease emphasised the distinction between their two experiences of cancer. The word 'different' was commonly used to highlight this.

*It was certainly a different experience, yes (Beth)*

*It was different ... I knew it couldn't be secondaries, because they say after five years, it's left your body (Diane)*

For three of the participants their two experiences of cancer were clearly separated in time. However, even Jenny, whose multiple primaries occurred within the shortest time span (three years), clearly differentiated between the two occurrences:



*It was a completely different one. ... because I wanted to know if it was a secondary. But it's not, it's a completely different one (Jenny)*

Information about the earlier experience of cancer was often condensed into a short, snappy summary that contrasted with the longer, more detailed descriptions given about their present symptoms:

*It happens so quickly, I don't think anybody realised I had cancer till after the operation. Even myself really, I didn't know I'd got it, because it did happen so quickly ... So then I had checkups, and then I was fine (Beth)*

*Once I had the operation and suchlike: that was it. We never even spoke about it. I went on the chemo and that was it as far as I was concerned. I had a growth in me stomach, it was took out and I'm still here (Iain)*

These summaries were typical in that they minimised the impact that first experience of cancer was perceived as having on the participant's life. This making light of their previous experience, and the distinct nature of the different experiences, was also emphasized through descriptions of a period of normality between the different episodes.

*I thought I been there and seen that and got the t-shirt, that sort of thing. And I got on with my life. I never thought about cancer again (Jenny)*

*I was fine, I went back to my normal things, it didn't really affect anybody, really (Beth)*

*I started to recover, slowly, I suppose, and got back into a routine. I got back on my feet again (Diane)*

This emphasis on the normalcy of the period between cancers was unexpected as research shows that fears about the recurrence of cancer are common (Dixon et al 1996, Johnson-Vickberg 2001, Webb 2005). Although concerns about re-occurrence were mentioned:

*Although it was different: it is always at the back of your mind (Beth)*

*I was always aware of it (Diane)*

The overall impression was of two distinct experiences of cancers that occurred in different locations in the body at different times.

No participant overtly commented on the obvious stark distinction between their previous experience of cancer, which had been treated and cured, and their present experience where their disease was deemed incurable with only palliative treatment options available. Nevertheless there were statements that hinted that this might be a latent underlying factor that made the two experiences distinct.

*And as I say they done the eight-hour op, took the kidney out, mentioned about the football and all, and I thought that was it ...and as luck is it hasn't come back for twenty-two years. This batch I've got now, I don't know (Iain)*

*But, as it happens ... it's come back with a vengeance really (Diane)*

The need for psychological support at the time of cancer recurrence is well documented (Dudgeon et al 1995, Dixon et al 1996, Herth 2000). However Dudgeon et al (1995) found a significantly increased ( $P < 0.05$ ) need for support with symptom control and maintaining function in cancer patients with disease progression compared to patients at the time of first recurrence of disease. This emphasises the need for increased support as a patient's disease progresses, and this increasing need might be one reason why patients did not see an obvious connection between their first experience of a different primary cancer with their present experience of palliative care. When prompted with a question like '*How do you think that the previous experience of cancer has affected what is going on for you now?*' replied:

*It hasn't really, to be truthful (Iain)*

*But that was bowel cancer. It was nothing to do with this cancer (Beth)*

That is, the clear focus on the different primary cancers as distinct experiences meant that the patients did not perceive their current palliative care needs as being affected by their earlier experience of a previous primary cancer.

Although the patients did not think that their first primary cancer affected their palliative care needs, they did indicate that there had been some effect on the initial period when the second primary had been diagnosed. One patient noted that it had affected the way she perceived and interpreted what was going on in hospital whilst undergoing the investigations and treatments for her second primary cancer:

*Anyway, the senior doctor came in, and he took loads of pictures, and the young doctor came in, and he took some too. And I thought, well, there's my answer isn't it. I thought I've got cancer again before I actually saw anyone (Jenny)*

This challenges the simplistic notion that information is held by health care professionals and given to patients (Payne 2002). Similarly Beth felt that she had deliberately ignored the symptoms of reoccurrence as she did not wish to face cancer again:

*And I realised I got those symptoms ... It's probably why I didn't go to the doctors sooner actually (Beth)*

It has been suggested that some people find the experience of cancer recurrence more upsetting than their initial diagnosis as they are less hopeful of cure and more fearful of dying (Mahon et al 1990), and Beth's reluctance to inform health care professionals about her recurrent disease did appear to be associated with these concerns. In contrast, Diane felt that it had led her to approach the second experience of cancer with a more positive outlook.

*Less worried. I wasn't at all worried, I was very positive ... I'd got the impression, that when you beat it once you might beat it again (Diane)*

Although she acknowledged that this early hope had not been fulfilled, she also stated her previous experience was still helping her to deal with the present circumstances, stating that she felt less frightened because of the increased insight her previous experience had given her.

*I'm not frightened of it, because I think I've got more understanding than what a lot of people do because it's happened so many times (Diane)*

These participants appear to have had a greater self-awareness about their condition during their second primary cancer. This appeared to have contributed to their open awareness about their condition. This can facilitate coping and help patients to live well in the present moment (Lin and Bauer-Wu 2003). This increased knowledge appeared to correspond to, and work in conjunction with, the increased awareness of the dying process due the multiple occurrences of cancer within the family reported above.

#### Nurse-Participant Perspective

There is a dearth of literature about the palliative needs of patients who have had multiple primary cancers and no nurse-participant spontaneously linked the experience of multiple primary cancers with an inherited predisposition to cancer. When asked directly they suggested that it made little difference to patient care. Several participants commented that patients often did not distinguish between multiple primaries and metastatic spread from the original tumour

*I think a lot of them to be honest just think they have got cancer and that it has spread. I really do think that (NP7)*

Whilst another commented that she herself perceived the care needs as being similar

*I haven't found that it has made much difference to the care. They sort of have similar needs emotionally. I don't think it makes much difference than looking after someone who has had primaries and secondaries (NP2)*

However the main reason that the nurses perceived little difference in patients' care needs was because they felt that it was the fact that the patients' cancer has become incurable that makes the care needs of palliative patients distinctive.

*I don't think it is addressed actually. ... But I suppose by the time they have got to us, it is not such a big issue (NP7)*

*To the care that we give? I don't know really because by the time they get to us it is usually pretty terminal isn't it ... The real shock is when, suddenly, they get to the end of the treatment and things really are progressing (NP9)*

The range of psycho-emotional effects described in individuals with a second multiple primary cancer included increased anxiety, resignation, strength, coping and acceptance. Despite this range of responses much of the data collected emphasised the potential increased strength and coping that the nurse-participants had seen in patients with multiple primaries. Many of the nurses thought that the resilience they had seen in patients who had had a previous primary was somewhat counterintuitive and not the reaction they themselves would have expected to observe.

*They are stronger, they are grateful that they have had, that they survived the first one and for that extra time. They will say, 'well I had breast cancer twenty years ago, so that is twenty years I might not have had'. That is a phrase that you hear quite often from someone who has got another cancer (NP1)*

*And it is sometimes quite funny the way people talk about it. It is 'oh, I've had this and then I had twenty odd years and now I have got it again'. 'And I thought I'd beaten it once but it has come back to haunt me'... it is really quite mind-blowing, that people, well casual is not the right word but how people ... cope (NP3)*

*But this particular patient ... had had a different cancer in the past and then been re-diagnosed with a different type of cancer and I thought that he would be more ... panicky, but he took it all in his stride and that surprised me... But that is maybe me being illogical, but he was coping better because he had been through this before and he thought he knew better what to expect (NP9)*

Nevertheless the nurse-participants felt that a previous primary could only partially prepare patients for palliative care. This was because the first experience of cancer had (by definition) been treatable and patients had not previously needed to fully face the issues associated with impending death. This suggests that the previous curable cancer had not fully prepared them for the dying role (Emanuel et al 2007) or informed them about their dying trajectory (Glaser and Strauss 1968). Hence the nurse-participants like

the patient-participants emphasised the difference between the experiences of different primary cancers and felt that it had a minimal impact on patients' care needs.

***Past Continuous with Present: 'BOGOF: Buy One Get One Free'***

As mentioned above, Harry was the only patient who had been told that his cancer was associated with an inherited susceptibility. He had been informed of this connection after he had been diagnosed with his second primary cancer.

*About this being inherited, a gene, it wasn't till I had this second cancer when the doctor talked about it (Harry)*

Although he described his second primary as '*a horrid shock*' (Harry); he used black humour to explain the link.

*The joke is because I've had one cancer and now I've got a second one it was a BOGOF cancer. Buy One and Get One Free (Harry)*

He used the term 'BOGOF' throughout the interview. He was the only participant who described the experience of two different primaries as one continuous episode rather than separate events (although Jenny had experienced her two primary cancers in a shorter time span).

*He (The hospital consultant) said, I think we can discharge you now, because it's been five years in the June and it is very rare that cancer comes again after five years. The next month we were down in the hospital again (Harry)*

*And I said I don't know how I will cope. All the time I've been dealing with it (Harry)*

Although Harry understood that his two separated primaries were probably linked by a common aetiology, like the other participants, he did not think that his experience of multiple primary cancers affected his interaction with the palliative care team.

As the nurse-participants were unaware of the potential link between multiple primary cancers and an inherited genetic predisposition to cancer they were unable to comment on how this effected patients care needs.

### ***Reflection on Temporal Analysis of Multiple Primary Cancers***

Although the information about the affect of multiple primary cancers from this study is limited there is a dearth of literature about the affect of multiple primary cancers on palliative care patients. The limited evidence from this study suggests that knowledge that multiple primary cancers are associated with a genetic predisposition to cancer had the ability to alter the way that the participants perceived their experiences. The four participants who made no connection with inherited disease underscored the differences between their two experiences whilst Harry accentuated the links, repeatedly calling his second cancer a ‘BOGOF’ and stressing the continuous nature of his lived-experiences of different cancers.

Knowledge of an inherited predisposition has been shown to give rise to increased feelings of not being cured for people with cancer prior to the development of a second primary (Bonadona et al 2002). For the participants in this study the experience of multiple primary cancers was a lived reality and not a future risk. Although three participants drew attention to the way their earlier experience of cancer had affected their initial approach to their second primary cancer, none of the patient-participants felt that it impacted on their present lived experience.

### **Discussion**

The chapter is called ‘The Missing Futures’ to spotlight the way that patients concerns about the future changed when they consider their disease through the genetic

lens. This temporal analysis has stressed the emotional dimensions of the care needs of palliative care patients. It shows how the knowledge of genetic predisposition to disease could change the meaning and significance of past occurrences of cancer for participants, and highlights how their concerns about the future expanded from an awareness that they themselves had a limited or ‘missing’ future, to fears that their relatives’ lives might also be curtailed by cancer.

One outcome from the temporal analysis was a better understanding of why the discourse of a family history of disease has not previously been a major focus of concern within palliative care. Outwith the genetic lens the participants described a range of effects: most participants described minimal effects from either previous occurrences of cancer within the family or multiple primary cancers on their present cancer journey. They described beneficial and detrimental aspects associated with an increased awareness of death on their present lived-experience. They wanted to support other family members who were concurrently living and dying from cancer. Only one participant (Anne) felt that the family history of cancer was a major factor in her present situation. She discussed how she continued to feel overwhelmed and distressed due to her family history of disease, despite ongoing support from the hospice multidisciplinary team.

The temporal analysis showed how the discourse changed when the topic of inherited genetic predisposition was raised. The temporal focus changed from how the past affected the present to concerns about the implications of the present for the future of other family members. It altered how patients viewed their family history of cancer and provoked concerns that other family members might develop cancer within the future.



Concerns that other family members, especially (adult) children, might develop cancer in the future were widespread in this study. It has been suggested that relatives' fears about inherited genetic predisposition increase as a patient deteriorates (Sanders et al 2003). Similarly, it has been suggested that the increased perception of risk at bereavement explains why a significant minority of people who attend genetic counselling do not obtain reassurance from being told that they are not at an increased risk of inherited disease (Rees et al 2001). Hence it is possible that the participants' awareness of their own imminent deaths had increased the salience of their fears for other family members. However, there was no direct evidence within the study to suggest that the participant's concerns were provoked by their knowledge that their own disease was incurable; rather the fears appeared to originate directly from their knowledge that cancer could be inherited in families with multiple occurrences of cancer.

The fact that many participants were dying with concerns about whether their illness had implications for their children's future health, irrespective of whether they associate their own, or their relatives' disease with a genetic predisposition to cancer or other causes, has real implications for patient care. This is because it suggests that the mere potential for cancer to be inherited, (not only the fear that one's family is at high risk of genetic predisposition), can increase anxiety about other family members developing cancer in the future. The fact that these fears were widespread suggests that it is important that palliative care services start actively managing these concerns.

Diane's experience presents one model of care that might be helpful to patients. Her concerns had been taken seriously. She and her family had been referred to a specialist genetic service. Although her concerns for her children persisted despite reassurance from the genetics clinic, Diane had found the reassurance given meaningful and

repeatedly mentioned that it had given her a reason to hope that the cancer would not reoccur in her daughters. For her, the concrete reality of previous deaths within the family was, to some extent counterbalanced by the reassurance given by expert advice. This suggests that open communication about the risk of genetic predisposition could be useful and reassuring to palliative care patients who had concerns about familial disease.

It is also necessary to consider what actions would be appropriate if a patients' family was thought to be at risk of heritable cancer. As discussed in the previous chapter (p159) many of the patients had discussed their concerns with other family members: urging them to be aware of the risk and to access any health promoting measures. Hence information about the services provided for family members at increased risk of future disease might be reassuring for patients. Patients might wish to consider genetic testing as this can allow other family members to more accurately assess their risk of future disease, or blood banking, which would allow family members to consider this option in the future.

The interview with Iain showed that there are patients with meaningful and emotive concerns for their children's future who have not previously had the opportunity to discuss these fears with healthcare professionals. Palliative care is often the last chance for these discussions to occur (Lalloo et al 2000). This indicates the need to start an open dialogue about inherited disease where patients can more fully express their concerns. Open communication about other aspects of the dying process has helped patients plan their affairs more successfully (Searle et al 1997) and could prove a helpful tool for care within the genetic lens.

With the exception of their concern about other family members, the patients did not think that their family history of cancer had affected their own care needs. This

finding is similar to the limited research literature that has studied the effect that predictive genetic testing has on people with cancer. Hallowell et al (2004) found that people in remission from cancer were not generally distressed when told they had a known genetic alteration as they had already acquired an image of themselves as being at increased risk of cancer reoccurrence. Bonadana et al (2002) and Hallowell et al (2004) both found that increased concern for relatives was the most frequently expressed concern in people who had tested positive for an inherited susceptibility to cancer. Findings suggest that these concerns may also be widespread in patients with a family history of cancer who have not undergone genetic testing.

Knowledge gained from the media and medical information had caused two participants to re-evaluate their family history of disease and consider the implications of an inherited genetic predisposition to illness more seriously. This shows that there is the potential for people's attitudes to their family history of cancer to change as and when clinical practice is able to harness the potential benefits of the increased knowledge about multifactorial disease (Bell 2004, DH 2003).

Findings also tentatively suggest that the meaning and significance of the experience of multiple primary cancers may change for patients. Although only one participant associated this experience with a genetic predisposition to cancer his account did indicate that being told he had a genetic susceptibility had made him re-evaluate experiences of cancer. Although the data available is limited it does indicate that knowledge of genetic predisposition has the ability to make patients re-evaluate different experiences of cancer, (that were separated in time and space), into one interwoven narrative.

Hence findings from this study both help to explain why the family history of cancer has been a missing discourse 'outwith the genetic paradigm' and suggest that

patients' concerns for the future health of other family members may mean that it will emerge as a more significant discourse when the slow but inevitable change (Bell 2004) to caring for people with cancer 'within a genetic paradigm' occurs.

## **Conclusion**

This chapter has presented the temporal analysis of the participants' lived experiences of cancer. The analysis demonstrates that knowledge of genetic predisposition to disease had changed both the meaning and the significance of their family history of cancer for participants. Knowledge of inherited genetic predisposition to cancer meant that the patient- participants were not only concerned about their own forthcoming death, but also to concern that other family members might develop cancer in the future. They had also re-evaluated their family history of disease. Concern for other family members who were living and dying from cancer was also important to participants.

Caring appropriately for patients who are concerned about the potential that other family members will develop cancer in the future presents a new challenge for palliative care services. (See Chapter Nine). However it is important to consider what patients understand about the aetiology of cancer and the potential for an inherited predisposition to disease when considering how to support them with concerns for the family's future health. This is the focus of the next chapter.

## CHAPTER EIGHT: THE MISSING FACTOR

(The Understanding of Cancer)

*Beware the Monocausal Fallacy (Anon)*

### Introduction

The aetiology of cancer is important because the understanding of an illness can affect the way that it, and the people who live with it, are treated and viewed by society, the healthcare system and themselves (Shiloh 1996). Aetiology means ‘the assignment of a cause: the rendering of a reason’ (OED Online accessed 19/3/07). The aetiology of cancer was an important and meaningful concern to all the patient-participants. This was because the patients expressed a real need to understand why they were dying. This was often linked with a sense of frustration that they could not find a clear, elegant answer as to why they had developed their particular disease.

*So I've read up on the prostate but even that does not give you a real answer as to why, you know like, why, why, why has my prostate suddenly got cancer? How have I got cancer? ... But nobody seems to be able to give me a direct answer for it (Leon)*

*(I) Do you know what causes cancer?*

*(Diane) No*

*(I) Do you think about it?*

*(Diane) All the time*

The patient interviews generated a lot of information about the patients’ understanding of cancer. This appeared to be because the question had an emotional as well as an intellectual aspect. Even the one patient (Grace) who did not wish to discuss the aetiology of their disease acknowledged that it was an issue that concerned and ‘scared’ her. Most patients had multiple and occasionally contradictory ideas about what had caused their own and their relatives’ cancer. They mentioned all the common causes

found in scientific textbooks (Kleinsmith 2006), except for aging and viruses, and included several idiosyncratic personal views.

This chapter looks at the patient-participants' understanding of cancer. It discusses two themes that emerged from the data. These were '*scepticism about given causes*' and a '*limited understanding of genetics*'. It concludes with a discussion about how the limited understanding of cancer as a multifactorial disease can be a factor that contributes to the family history of cancer being a missing discourse within palliative care.

## **Emerging Themes**

### ***Scepticism about given causes***

A consistent and dominant theme that was interwoven throughout the patient data was scepticism about given causes. This included a general scepticism that the cause of cancer was known.

*I've got no answer. I've got no answer to it, and I don't, can't see how other people have got answers to it. Cancer just occurs (Leon)*

*No, nobody knows what causes cancer. All these boffins: Oh, this has caused it, that has caused it. I look at it like the chickens and the eggs and God knows what (Harry)*

*Because, they don't really know what causes cancer (Anne)*

*I don't know the answer. I puzzle it but I don't know. I don't know if anybody really does know? (Jenny)*

Beliefs about illness are rooted in the cognitive world of an individual and are shaped by both personal experiences and by culture (Richer & Ezer 2000). They are primarily conscious, rational representations that influence the appraisal of current events (Richer & Ezer 2000). Health education aims to promote public health by

reducing adherence to practices deemed harmful to health and encouraging health enhancing activities (Frankel et al 1991). However, health promoting messages in the media are often very general, obtained from varied sources and change frequently (Arman et al 2006). The seemingly endless media focus on different and sometimes conflicting causes of cancer has increased the sense of scepticism about public health messages (Crossley 2003). This may help explain the widespread scepticism about the different causes of cancer discussed in this study. The given causes included a) historical concepts b) lifestyle factors c) environmental causes d) iatrogenic causes and e) genetic causes.

#### a) Historical Concepts

Historical explanations for the aetiology of cancer can still be influential decades or even centuries after they had been scientifically disproven. In the Sixteenth century scientific theories suggested that cancer might be contagious as when it was recognised that some cancers, including breast cancers, occurred in families or particular communities (Olson 2002). This was shown to be false in 1771 when James Nouth removed cancerous tissue from a patient and implanted it in his arm to decide whether familial breast cancer was due to contagion or to inherited factors (Olson 2002). However, it would appear that concerns about cancer being contagious remain, and two participants in this study felt a need to refute this.

*I couldn't touch somebody today with cancer and then find out the next day that I've got cancer tomorrow. It's not like that (Harry)*

A later eighteenth century theory proposed that cancer was due to localised trauma or injury. This theory persisted in the medical literature until the 1920's despite evidence from the testing on animals that it was implausible (Greaves 2000, Lee 2000).

Injury, however, was also mentioned as a possible cause of cancer by one patient in this study.

*I was told that everybody has got cancer in the body and all it takes is a slight bump. ... I was always frightened of falling over and hurting myself because I thought I was going to have cancer. I have known people who have been hit by a cricket ball, a golf ball and they finished off with a cancer. I think, you thought that was true but ... (Leon)*

Wold et al (2005) found over twenty percent of six hundred and seventy cancer survivors (in North America) thought that physical injury could predispose to cancer. Although these historical theories were treated sceptically and refuted by the patient-participants, the fact that they were commented on as potential causes of cancer alongside the recent understanding of cancer as an inherited genetic disease, illustrates that patients were grappling with disregarded old scientific theories alongside complex new ideas.

#### b) Lifestyle Factors

All the patients were aware of health promotion messages that associated cancer with lifestyle factors such as smoking, diet and exercise (WCRF/AICR 2007). However the underlying theme to emerge from the patient data was a widespread scepticism about these given explanations for the aetiology of cancer. This appeared to be because the given explanations did not tally with their own life experience. For instance, both smokers and non-smokers expressed scepticism about the link between cancer and smoking.

*They are always running smoking down. They say it causes cancer blah, blah, blah. But everything causes it. It is just an excuse as far as I'm concerned. They are just using cigarettes as an excuse because everything causes cancer (Iain)*

*You know passive smoking: it causes cancer but I say no ... I've been a passive smoker all me life, even when I was young. ... So you was living in an atmosphere of smoke ... But I haven't got lung cancer through it. ... I think*



*unless they can define, really, really define, that smoking causes cancer I'm very sceptical about it (Leon)*

This scepticism extended to patients who had altered their lifestyle in the hope that it might prevent or postpone the spread of their disease. For instance, Finlay, quoted below, had been to an alternative therapist and made major alterations to his diet since his initial diagnosis. Nevertheless he remained sceptical about the link between his lifestyle and the origins of his own cancer.

*I do ask the question 'Why me?' because a lot of people abuse their body so much, drinks, smokes and eat all sorts of junk food and it seems to me a problem because I NEVER did; I would eat home cooking and try and keep myself fit (Finlay)*

Harry commented that his experiences since developing cancer, especially his experiences as a patient, had challenged his previous views that a healthy lifestyle could prevent or reduce the risk of cancer.

*The thing that amazed me, the young man who had a reasonably clean and moderate sort of life; they couldn't do his operation, but the bloke ... who ate fatty foods, smoking and drinking, they could operate on him (Harry)*

Claire was the only participant who clearly and unequivocally linked her own and other family members' cancer to a shared lifestyle factor: smoking. However, despite the widespread scepticism about the association between their lifestyle and the development of their disease, there was some evidence that patients and their families had altered their behaviour due to health promotion messages about cancer aetiology being associated with lifestyle factors.

*The daughter packed in smoking in the end. The son-in-law ... he finally packed it in ... you weren't allowed in the house because of smoking (Leon)*

And that some participants were trying to promote healthy habits within their families.

*I encourage my grandkids to eat natural stuff. Chocolate, stop eating chocolate and sweets and things like that and try eating fruits and vegetables more than ever before (Finlay)*

Other participants drew attention to their resistance to health promotion messages, especially those about stopping smoking.

*I said I'm not going to pack in smoking just because I've got bloody cancer; what is the bloody point? (Iain)*

Although Iain also said that his resistance to changing his lifestyle had caused friction within his family, because other family members did perceive a link between cancer and smoking.

*Me daughter wants me to pack in smoking. I say to her it is a waste of time that is. It is too late anyway I've got cancer (Iain)*

Resistance to health promoting advice about lifestyle is widely documented amongst the general public (Williams 1998, Crossley 2003). It has been described as 'a symbolic form of transgression' (Crossley 2003: 512) that enables people to assert the moral value of independence and individual rights as being more important than an unthinking commitment to the normative value of health. However this was not apparent in this study, where participants expressed scepticism about the scientific evidence that linked cancer and smoking, and emphasised a pragmatic acknowledgement that it was too late for a change in lifestyle to affect the outcome of their disease process.

### c) Environmental Causes

There was a widespread awareness that environmental factors could be associated with the aetiology of cancer. Radiation and chemicals were frequently highlighted as potential causes of cancer. The environmental causes given were often very general, sometimes vague and again often considered sceptically.

*And the environment as well (Finlay)*

*I don't really know. Whether it is the environment, whether it is the H-bomb, experiments, DDT on crops: I just don't know. It is a puzzle (Jenny)*

Nevertheless some patients had clearly wondered about how the environment in which they lived and worked might have contributed to the development of their cancer. Some of these ideas fitted with the scientific literature about the causes of cancer (Kleinsmith 2006).

*I suppose I have thought about what I have done at work. ...Working in cyanide ... Yes, chemicals. Could they have caused this? (Keith)*

Other theories were more idiosyncratic:

*There is so much, you know, microwaves and computers, and all these sorts of things, and I used to think to myself, was it the combination of the connection between the metal in my bra and all these vibrations and things that triggered something off (Anne)*

Epidemiological evidence suggests that environmental factors have a significant role in the development of cancer (Kleinsmith 2006, WCRF/AICR 2007). However the large number of potential environmental contributors to the aetiology appeared to increase the participants' scepticism about any one given cause.

#### d) Iatrogenic Causes

Four of the twelve participants had also wondered whether some of the cancer in their family had an iatrogenic cause.

*Personally, I think, I was on the HRT for 12 years, and then I came off it. And I think that it's that, that caused it (Anne)*

*Because the chemotherapy I was on twenty-two years ago was experimental. And I feel as though that has caused this batch (Iain)*

There was less scepticism about iatrogenic causes of cancer than any other category, and three of the four patient-participants who discussed it as a potential cause of cancer

appeared to believe it was one of the more likely and credible explanations for their illness.

#### e) Genetic Causes

It was notable that the only participant (Harry) who had been told that his cancer was due to an inherited genetic predisposition to cancer (by the registrar in his oncology team) remained sceptical about this information. He had been predeceased by five first-degree relatives from cancer (mostly stomach cancer), and had two other siblings who were concurrently living with cancer.

*I only talked to that doctor there and he made a note of it. But and he did come back after a couple of days. And he said; 'I'm beginning to wonder whether the cancer is genetic'. I said 'Well, our family has had it' (Harry)*

However Harry appeared to think that the idea of an inherited genetic predisposition to cancer was an unproven theory, and that cancer was primarily caused by smoking and drinking despite having led a '*moderate lifestyle*' himself. He repeatedly described the doctor as '*young*' and emphasised that he was a '*junior registrar*'. He stated that the doctor '*was trying to make a study of whether cancer is genetic*'. Nevertheless he did not disregard the doctor's words as the concept of a genetic predisposition to cancer appeared to resonate with his own family's history of cancer and he was willing to contemplate it as a possible reason for his own illness saying:

*I think they have to ask patients like me, and put the record down. If your family have had, if any members of your family have had cancer in the past (Harry)*

Harry felt optimistic that knowledge of the genetic origins of cancer could lead to new treatments and noted:

*I would think if they do discover it is a gene, which goes through various families, then I think geneticists will find something to prevent it' (Harry)*

Therefore, despite his understanding that *smoking, alcohol and diet* were the main causes of cancer, Harry now wondered whether a genetic predisposition to cancer was significant for his family as he, and his family, had always '*lived moderately*'.

*... Well I'm wondering myself sometimes whether it is a gene that goes through the family that causes this. I mean, I don't know (Harry)*

He balanced his scepticism with his belief that his cancer might be genetic by saying '*Well, it's very odd. I don't worry about it*', although he did acknowledge that it might worry '*a lot of people*'.

It was notable, and somewhat paradoxical, that Harry who had been informed that that his cancer was associated with an inherited genetic predisposition to cancer appeared more sceptical about this than other participants who discussed the fact that cancer could be associated with an inherited genetic predisposition to cancer. The understanding of cancer genetics is discussed below (p189).

### Reflection on Scepticism about Given Causes of Cancer

Beliefs can be considered as the 'truth' of a subjective reality (Wright et al 1996). Scepticism is closely related to trust and the ability to believe the scientific evidence or 'truth' of official health promotion messages (Crossley 2003). It has been shown that conflicting media advice has reduced the ability of the general public to trust official sources, and that this distrust extends to health care professionals who were seen as complicit in this process; for instance, by being influenced by drug companies (Crossley 2003). This may have influenced the participants who attributed their own illness to iatrogenic causes. The widespread scepticism about the scientific understanding of cancer evident in this research may also be related to the study being

located within a hospice, where by definition the patients had advanced disease that could not be cured by modern science or medicine.

The pervasive scepticism about the scientific understanding of cancer is an important finding, as it highlights that doubt, scepticism and misunderstandings about an inherited predisposition to cancer need not be associated with factors that are specific to genetics like the complexity of the science or the distrust engendered by the eugenics movement. Rather they may be associated with a more widespread scepticism about the aetiology of cancer, which is perhaps associated with distrust of official health promotion messages. This may be due to the wide variety of health prevention messages (Williams 1998, Crossley 2003).

There was absolutely no indication that any patient was aware that recent scientific research considers the development of cancer to be a multi-step process: that cancer cells develop a collection of distinctive traits that develop over time due to a series of alterations to the DNA and that there are many factors that can alter the probability that each of these steps will occur in an individual (Kleinsmith 2006). Reports about multifactorial influences on cancer are rarely given media coverage (Peterson and Bunton 2002). Hence the participants in this study who were sceptical about any of the given causes of cancer as a monocausal explanation for their own disease process appeared completely unaware that this was in accord with emerging scientific thinking.

This chapter is called the 'The Missing Factor' to highlight the lack of awareness about multifactorial aetiology of cancer shown by the participants. This misunderstanding is crucial, not only because it may contribute to the scepticism that pervaded the patients' perception about the causes of cancer, but also because it is a fundamental concept when considering the potential for an inherited genetic

predisposition to cancer. It contributed to the participants' limited understanding of genetics, as demonstrated below.

### ***Limited Understanding of Genetics***

Ten of the twelve patients spontaneously mentioned genetics, genes or having cancer 'in the family' as a potential cause of cancer, although only two (Diane and Harry) had discussed the possibility with healthcare professionals. This widespread awareness of genetics as a cause of cancer is commensurate with other studies that show that the widespread media coverage of cancer genetics is both raising awareness and causing concern about inherited disease (Emslie et al 2003, Bankhead et al 2001). However the understanding of cancer genetics was very limited and only a few participants choose to elaborate on the topic. They struggled to clarify their ideas, both when talking about genes and when discussing inherited genetic predisposition to disease.

### **The Concept of Genes**

The few patients who discussed genes clearly struggled to conceptualise a gene. Leon described genes as though he thought they were a discrete organ that moved around damaging the body.

*There should be a gene ... where the cancer will occur. If it is in your breast you will get it in your breast, if it is in your lungs you will get it in your lungs ... Or if there are different genes for the different cancers I wouldn't like to say (Leon)*

Diane described her cancer genes as an alien on three occasions. In this image the gene does not only appear to be a discrete entity but also an entity that is foreign to the body.

*Well, it is like you have rogues genes that you carry. It's like an alien, I suppose. It keeps coming back to me; I don't like it (Diane)*

This idea of the gene as an alien invader that attacks the self is very different to the dictionary definition of ‘the basic unit of heredity in living organisms’ (OED Online accessed 17/6/08) and shows that genes are not always conceptualised as being integral to self. A contrasting notion that genes predestined people to cancer was also raised. The concurrent ongoing media coverage of The Human Fertilisation and Embryonic Authority’s decision to permit embryo screening for cancer ([www.bbcnews](http://www.bbcnews) accessed 10/05/06) may have enhanced this concept of genetic predestination, as opposed to predisposition to disease.

*Because your genes rule your life, don't they? ... They build you to what you are: whether you are going to be ill, seriously ill, or whether you are going to live till you are one hundred. It's your genes ... that progress your life ... And they can find out, or they are supposed to find out that when you are born then they can look for the cancer gene: The genes which causes cancer (Leon)*

The way individuals visualise and conceptualise genes and genetic disease may have the potential to affect the way they cope with familial cancer. The power of cancer imagery has long been recognised (Sontag 1978) and guided imagery, a technique that harnesses the power of the mind to form helpful mental representations of objects or situations, has been shown to reduce stress, anxiety and depression in cancer patients (Roffe et al 2005). Images of treatment acting as a defence against alien cancers can be effective in allowing patients to fight disease (Goldberg 1990). Other studies have reported a comparable confused conceptualisation of genes in people with familial heart disease (Emslie et al 2003), and in studies of lay knowledge about cancer risks (Adlard and Hume 2003). This suggests that consideration of patient’s understanding of genes might be important when discussing genetic predisposition to disease.



### Assessment of Familial Risk

There was also confusion about patterns of inheritance and how this might affect other family members. In the following extract Harry is talking about the disease in his wife's family (his sister-in-law and niece-in-law).

*It comes out every other, it's skipped a generation. Her grandmother had it but her daughter hasn't had it and she has got it now. All I'm saying is that, if she marries and has a daughter, her daughter might marry and pass it on to her daughter ... that must be a gene that passes on through the family (Harry)*

Although recessive inheritance of cancer is known to occur in certain rare cancers like xeroderma pigmentosum (Kleinsmith 2006), the distribution of cancer within his wife's family would be suggestive of sporadic cancers rather than inherited predisposition. As discussed, Harry had been told that his cancer was possibly genetic but did not have the knowledge to differentiate between the risk to his blood relatives and his wife's blood kin. The fact that he made no distinction about the aetiology of disease in his family where eight first degree relatives had cancer and his wife's family who only appeared to have two cancers in three generations, again highlighted the fact that he had no concept of multifactorial disease causation and was struggling with monocausal explanations for cancer.

Although there was a widespread awareness that cancer could run in families, there were surprisingly few attempts by participants to explicitly link the pattern of cancer within the participant's family with knowledge about how genes were linked to disease causation within families. However parental cancer appeared to be particularly important when patients considered why they had developed cancer:

*I think it's hereditary, because I had it, and my father had it (Beth)*

*So I ask the question 'Why me?' but my mother did die of cancer (Finlay)*

For these participants one parent with cancer was enough to raise questions about inherited disease. Conversely, the absence of parental cancer was seen as negating the likelihood of inherited genetic disease despite multiple cancers in the family.

*It's all on my mother side, yes ... But I can't find that any of my mother's previous family ... had cancer. But there is a lot in my generation (Jenny)*

*But my mother and father didn't have cancer. It seems funny that it should be me, my sister, and my two brothers that have developed some sort of cancer (Anne)*

It is important to note that awareness that cancer could be an inherited genetic disease did not automatically mean that the participants linked their own family history of cancer with a genetic cause, even when there were multiple experiences of cancer within the family. For example Anne was clearly aware of, and informed about, the risk of inherited disease with breast cancer.

*And today they say it's probably about your genes, genes... You've got bad genes they say (Anne)*

However she had disregarded it as an explanation for her cancer because neither of her parents had cancer, despite the fact that her nephew, niece and all her siblings had developed cancer (several at a young age). In fact Anne, like most of the participants, was sceptical that the cause of cancer was known or understood.

*They don't really know what causes cancer ... I think it could be one in a million things ... I think it's so complicated, complex. It might be a hundred years time, then they might have solved it (Anne)*

However it was when multiple occurrences of cancer occurred in conjunction with parental cancer participants were most likely to associate the family history of cancer with a genetic origin. For instance, Iain was discussing his siblings' and parents' cancers when he drew attention to his fears that his children might have a cancer gene, and although Harry was sceptical about an inherited susceptibility to cancer he

appeared more open to the possibility when discussing the multiple occurrences of cancer within the family.

*That's right, four sons and two daughters. Mum and Dad and (brother's) and (sister) are deceased ... Cancer is especially to you, so it must be your genes I reckon within the family (Harry)*

### Reflection on the Limited Understanding of Genetics

These findings illustrate the very limited understanding of cancer genetics in the patient-participants. Participants were unable to clearly conceptualise a gene and had a poor understanding of how to assess the risk of inherited cancer. This is important because the accurate assessment of risk depends upon the understanding of genetic inheritance.

The participants' limited understanding of cancer genetics is consistent with other studies that show that relatives of people with adult onset multifactorial diseases like cancer do not calculate their risk using bio-scientific models (Walter et al 2004). A synthesis of the literature suggests that people develop a sense of vulnerability to disease through the salience of their family history, which is interpreted within their personal understanding of causation and inheritance (Walter et al 2004). In this study the salience of disease was high for all participants (who all had incurable cancer and a family history of cancer) nevertheless they were sceptical about genetic, (and other bio-scientific factors), that may have contributed to of the cause of their disease. This suggests that a high salience of disease is not, in itself, enough for participants to believe that the cancer in their family was due to genetic causes.

Parental illness appeared to be the most important factor that participants associated with genetic predisposition. Multiple occurrences of cancer within the family did appear to increase the likelihood that participants would attribute their disease to a possible genetic link – but only if they occurred in conjunction with parental disease

and many only discussed the possibility in passing. They were sceptical about the possibility of genetic causes of cancer alongside other explanations for the disease.

Adlard and Hume (2003) found that relatives of people with cancer had a better basic knowledge of cancer than the general public. They suggest that people learn from their relatives' experiences. Findings from this study, where participants were both relatives of and people who were living with cancer, suggest that it is possible to interact with cancer services over decades and still have a very limited understanding of why cancer occurs within a family. Nevertheless Adlard and Hume's (2003) finding that relatives know more than the general public suggests that if patients were better informed about the multifactorial nature of cancer and the role inherited susceptibility to disease played in familial cancers, they might be able to pass this knowledge onto relatives. This is especially important with respect to inherited genetic predisposition as it can affect the way people manage their disease and risk within the family (Walter and Emery 2005) and as healthcare professionals are not able to contact relatives directly about disease risk (Hope 2004). However the poor understanding of the aetiology of cancer limited their ability to assess this risk accurately.

## **Discussion**

It has been claimed that 'inquiry into patient health beliefs is perhaps the most powerful foundation for collaboration between patients, families and health care professionals' (McDaniels et al 2006: 175). It encourages mutual trust and collaborative relationships that help professionals clarify patient concerns about their disease (McDaniels et al 2006). Health beliefs are culturally embedded (Conner and Norman 2005). Hence consideration of the understanding of familial cancer is important when assessing the cultural component of care for palliative care patients, where culture is

defined as ‘the distinctive ideas of a particular society, people and period’ (OED Online 2008).

### Behaviour and the Understanding of Cancer

There is a common sense appreciation that human behaviour is associated with attitudes and beliefs (Ajken and Fishbein 2005), however studies have shown that general beliefs and attitudes correlate poorly with specific actions, and that people who hold the same beliefs can act in different ways. Despite this, strong correlations are found between attitudes, beliefs and behaviour when behaviour measures are representative of a broad behavioural domain (Ajken and Fishbein 2005). Hence attitudes and beliefs can broadly predict behaviour. However it is known that attitudes about disease threat alone are often insufficient to motivate individuals towards different patterns of behaviour (Egger et al 2002, Conner and Norman 2005). Other factors that are known to influence health behaviour include demographic, personality and social factors: despite this, it remains important to pay attention to cognitive factors like the understanding of/and attitude to disease because they differentiate between individuals from the same background, are open to change and represent one route to influence health behaviour and concerns about disease (Conner and Norman 2005).

It is not known exactly how understanding, beliefs and attitudes interact with other factors to influence behaviour, and several models have been constructed to try to explain the links between health beliefs and behaviour. These include, The Health Beliefs Model (Rosenstock 1974) and The Theory of Planned Behaviour (Ajzen and Fishbein 2005). The Health Beliefs Model suggests that the perceived severity of a health concern and the perceived susceptibility to the health problem, alongside the perceived benefits and barriers to acting on that concern, influences behaviour (Egger et

al 2002). That is, for behaviour to change an individual must have the incentive to change, must feel threatened by their current situation and must feel that change will be beneficial and at an acceptable cost (Egger et al 2002).

There has been limited use of health belief models in the context of genetic predisposition to disease (Janz and Becker 1994) and this study did not aim to examine the links between the participants' beliefs and their behaviour. Nevertheless it was noteworthy that ten of the participants were aware that their family history of cancer might/could be associated with an inherited genetic predisposition to disease but only one had raised these concerns with healthcare professionals. In the light of the widespread scepticism about the known causes of cancer shown by the participants, and their limited knowledge about an inherited genetic predisposition to cancer, discussion about why so few participants had acted (even by initiating discussions with nursing staff) on their concerns about having cancer in the family are perhaps superfluous.

However, phenomenological enquiry draws on many sources of meaning (Van Manen 1990), and consideration of how the participants understanding of cancer affected their care needs was integral to this study. Components from The Health Beliefs Model have been used as framework to structure this discussion. It must, however, be noted that they have been used with the intent of systematically discussing the information obtained, (not with the intent of predicting behaviour).

- Perceived Severity: For the patient-participants in this study the perceived severity of the threat of cancer was high. They were aware that their illness would cause their death and were actively dealing with the physical and psychosocial sequelae of advancing incurable disease. They were also concerned that other family members were at risk of cancer in the future.

- **Perceived Susceptibility:** The perceived susceptibility to inherited genetic disease was very variable in this study. Few participants were concerned about inherited susceptibility with regard to their own illness but there was widespread concern about other family members developing cancer in the future: especially children. This had prompted several participants to discuss the potential for inherited disease with their adult-children and provoked significant distress for Iain when he contemplated his young-children's risk of susceptibility to future disease.
- **Perceived Benefits:** All the participants who had discussed hereditary cancer with other family members had done this to encourage relatives to access screening and regular checks. They appeared to perceive early intervention and diagnosis as a benefit for relatives. Diane was the only participant to perceive that her family might benefit from contact with genetic counsellors.
- **Perceived Barriers:** Scepticism about the medico-scientific understanding of cancer was widespread. Scepticism was present regarding all of the known predisposing factors for cancer including lifestyle, environmental and genetic factors. This could constitute a barrier to accessing further information about the aetiology of cancer from healthcare professionals and reduced the perceived utility of health-promoting health behaviours for the patients and their children. The poor knowledge about the aetiology of cancer could also constitute a barrier. No participant showed an understanding of cancer as a multifactorial disease and the understanding of genetics and inheritance was poor. Concern about the impact of knowledge of inherited disease on children was also a barrier for Iain. He

felt the distress that it would cause to his children outweigh any potential benefits of informing them of inherited risk

These barriers appear to have been significant for many of the participants. Despite the severity of the threat and the concerns about the susceptibility of other family members expressed by many participants, only Diane had raised her concern with healthcare professionals. Similarly, despite the suggestion that advancing incurable disease might provoke anxiety about familial disease in patients and families (Sanders et al 2003, Rees 2001), and awareness that palliative care might be the last opportunity to identify people who are at risk of an inherited predisposition to cancer for a generation (Lalloo et al 2000, Kirk 2004a), healthcare professionals had only raised the issue of inherited genetic predisposition with one participant: Harry.

It has been claimed that as society becomes increasingly 'geneticized' knowledge about genetic predisposition to multifactorial disease has the potential to become increasingly influential to the way patients perceive their disease and the risk to other family members (McDaniels et al 2006). This study suggests that the scepticism of palliative patients about bio-scientific causes of cancer, alongside a poor understanding of cancer genetics, may be a barrier to patients acting on these concerns. This is an important finding as communication with terminally ill family members about the risk of familial disease was identified by Hallowell (1999) as a reason why people contacted genetic services. Hence patient scepticism about the causes of cancer have the potential to block relatives access to genetic counselling and therefore, their access to risk reduction measures.

One potential reason for scepticism is the multiple and often conflicting health promoting advice that people are given (Crossley 2003). This emphasises the need for



good patient education about cancer being caused by a series of steps, each of which might have a separate trigger. This would allow the various proximal causes of cancer that were known to all the participants to be held within an explanatory framework, potentially reducing scepticism (Rees et al 2007).

This study suggests that patients with a family history of cancer may be aware of the potential risk of inherited disease but sceptical about this risk and the efficacy of acting on their concerns. That the lack of knowledge about multifactorial causes of disease can act as a missing factor, preventing patients from evaluating their family history, or considering how an inherited susceptibility might interact with other lifestyle and environmental factors to promote disease within the family.

Finally, the findings from this small study suggested that individual perceptions of genetics can be diverse: ranging from alien invaders to concepts of predestination to cancer from conception. This emphasises that individualised assessment with regards to the cultural aspects of patients' understanding of cancer genetics is as important as with any other aspect of care. Listening to patients and reflecting on their perspective should be the starting point of all health-promoting education within palliative care (Kellehear 1999).

## **Conclusion**

This chapter highlighted the patient-participants' scepticism about the causes of cancer and documented their limited understanding of cancer genetics. It suggests that the lack of awareness of the multifactorial aetiology of cancer is a 'Missing Factor' that act as barriers that prevent patients raising their concerns about familial disease. It highlights the need for individualised culturally appropriate care to take account of

patients' differing understandings of familial cancer when evaluating the care needs of patients with a family history of cancer.

This reinforces the need to ensure that patients have the opportunity to disclose and explore fears about risk and ensure that they are properly evaluated. A core competency for nurses is to be able to identify clients who might benefit from genetics services and information (Gaff 2005). The nurses' perceptions of the care needs of patients with a family history of cancer are the focus of the next chapter.

## CHAPTER NINE: THE MISSING AGENDA

*He who knows not and knows not he knows not: He is a fool – shun him*  
*He who knows not and knows he knows not: He is a student - teach him*  
*He who knows and knows not he knows: He is asleep – wake him*  
*He who knows and knows he knows: He is a wise man – seek him*  
(Variously attributed to Confucius, Socrates or an Unknown Persian Source)

### Introduction

Lived space is the existential theme that refers to the lived experience of the world that the research participants inhabit (Van Manen 1990). There are cultural and social conventions associated with physical spaces that give places qualitative dimensions. Enquiry into the lived space of a phenomenon enhances the quality of meaning when researching lived experience (Van Manen 1990). The lived space within which this research took place was a hospice. In this study only the nursing staff were asked about whether they felt that palliative care was an appropriate service to address the issues relating to genetic predisposition to cancer, hence the spatial analysis considers the question primarily from their perspective. This chapter firstly highlights that the patients felt they were receiving expert care then, discusses five themes that emerged when the nurses reflected on the care required by patients with a potential inherited genetic susceptibility to cancer.

This chapter presents the nursing data about the care of families with an inherited predisposition to cancer. It uses Benner's (1984) model of clinical development 'From Novice to Expert' to develop to argument that, although the care given outwith the genetics lens was expert, the nursing staff were novice with regard to the care of patients and families with a potentially inherited predisposition to cancer.

## Emergent Themes

### *Family Care Integral*

Care of the family is integral to the definition of palliative care (NCPC 2007, WHO 2002). All of the nurse participants acknowledged that care of the family was a central aspect of the care given:

*Everything we do in palliative care, the education that we get on it, it's the family and the patient are a unit (NP5)*

And that caring for the family was integral to patient care:

*And then the patient is much better because the family, I think, supply the security for the patient and I think that is very strong. I do really (NP5)*

However, they stated that in practice the nursing care of the family was often constrained by the location where the care occurred. All the nurses who worked in the community palliative care team stated that care of the family was fully integrated with the care of the patient. They were aware that it was essential to ensure that the family were fully supported, to enable them to care for the patient at home where they are the primary caregivers (Doyle 2005)

*I think that our role is very much caring for the family ... As much as caring for the patient: because, especially if somebody wants to stay at home ... I think it is important that the family are cared for... I think they need the maximum support that is available to the family. You have got more chance of a patient being able to stay at home (NP4)*

The nurses who worked in the inpatient unit also emphasised how integrated the care of the patient and family could be:

*The first priority is, of course, the patient, but there is a huge percentage of you goes to looking after the family ... So for me I am constantly looking after the patient but constantly seeing how the family and relatives are affected by the situation (NP6)*

In contrast, the nurses who worked in the day centre acknowledged that their work was often more focused on patients, as the purpose of day care can be to give patients respite from their families (Payne 2006).

*The emphasis in the day centre is more on the patient ... often the patient is trying to get away from the family, because they are over-loved and over-smothered and people talk about it all the time or it is ignored and the disease is not acknowledged, so they can come here and talk about it. But... it is very nice if you do see some of the family (NP7)*

However, even the day centre actively attempted to integrate families into care services (Payne 2006), including offering complementary therapies and counselling with trained counsellors:

*We do complementary therapies, they come to outpatients, obviously advice, all sorts of advice, including on the phone. There is some patients that I do a weekly phone call to the family ... Some of them come in with them ... we will talk about drugs and just what is going on (NP7)*

Hence all of the nurses were aware that relatives needed support, both for their own sake as well as to enable them to be close to and support the patient (Andershed 1999 quoted Andershed 2006, Panke and Ferrell 2005).

### ***Palliative Care: An Inappropriate Setting for Risk Assessment***

All of the nurses were aware that the knowledge of inherited susceptibility to cancer had the theoretical potential to provoke new fears (Peterson and Bunton 2002, Henderson and Kitzinger 1999).

*I guess it might bring more anxiety. There is more information on genetics and ... I suppose it makes people think more. When they have had it and this relative has had it, saying well what do you think? What is going on? They may need more support (NP2)*

*I think there are many, many people who are afraid because it is a known factor that breast cancer can be hereditary. And I think people on the whole do ask that question (NP5)*

Despite the awareness that the care of the family was integral to palliative care (NCPC 2007, WHO 2002) the nurses did not think palliative care was an appropriate setting for risk assessment of inherited genetic susceptibility. All the nurses expressed reservations about discussing genetic predisposition within a palliative care setting and several participants felt a palliative care setting was definitely inappropriate. There were two reasons given for this: firstly, that genetic risk assessment was a separate speciality with its own expertise which they did not possess.

*That (the) genetics team have got that in-depth knowledge and that experience and I think it is a case of referring it on to the specialists (NP4)*

*I think it would be better with geneticists ... Because it is so complex (NP7)*

*I mean all we can do as nurses is make ourselves as aware as much as possible so we can act within our scope ... You know they (genetic specialists) do a lot of work, in terms of looking at who ... whether people need to be screened and whether their risk is any greater. Or whether it is just random: there is no familial link at all (NP4)*

Low confidence levels about their ability to deal with genetic issues has been shown to be widespread in nursing (Burke and Kirk 2006) and in palliative care nurses in particular (Clifford et al 2007).

The second reason given was that it was inappropriate to introduce the topic of inherited disease whilst the patient was dying. The fact that it was obviously too late for patients to benefit was regularly highlighted.

*It is much, much better earlier because you want to prevent it don't you (NP7)*

*I think it should be done long before palliative care personally ... Because it is really too late, isn't it (NP1)*

*If you have cancer in the family and perhaps you are worried that you might have it then a palliative care hospice is not the right situation. No: Because we are at the other end of the journey (NP3)*

The main barrier to raising the topic of inherited disease with relatives was the emotional involvement of families with the dying patient, and the nurses felt that dealing with the death itself could be an overwhelming issue for many families

*It would be better to be somewhere where it was a little less emotive: ... Because I think you can get a bit, well, overwhelmed here at times. And you can lose perspective here at times (NP9)*

*Not really, is my answer. ... They (Family) are more thinking about the patient dying and how they can help the patient (NP6)*

One nurse elaborated on this by suggesting that raising the topic of inherited susceptibility to disease near death might lead to an association with a predetermined death, rather than the potential for early disease identification and increased expectation of cure that is the rationale for identifying people at risk (Bell 2004).

*Being in palliative care ... it might be a bit too late. They wouldn't have hope: they would come to see death as the end, as opposed to getting wrapped in screening and treatment ... It could really depress their whole life (NP8)*

Three nurses commented that the potential distress associated with the topic had prevented them from mentioning the possibility of inherited susceptibility (see also exemplar-case two below).

*We have actually had a study day here about it (genetic predisposition) so I have thought about it but never felt it necessary to raise it, or appropriate to raise it, would perhaps be better (NP7)*

One participant was also concerned that introducing genetic issues could open up divergent care needs between patients and their family that might be detrimental to patient care.

*I think it would distract from what we are trying to do to some extent. ..., you can imagine someone on a ward bringing all this up ... and trying to sort all that out and not concentrating on the patient who is actually dying (NP7)*

These concerns are similar to concerns expressed in Arden-Jones et al (2005) study that investigated the impact of genetic testing at the time of initial cancer diagnosis. They suggest that this was ‘too much too soon,’ and that the emotional overload in coping with the cancer diagnosis meant that offering genetic testing would add too much additional stress. Dying is also stressful for patients and families (Vachon 2005a,b, Duhamel and Dupuis 2003) and these participants appeared to feel that raising the topic of inherited disease in palliative care was ‘too much too late’.

Identifying clients who might benefit from genetics services and information is a suggested core competency for all nurses (Kirk et al 2003, Gaff 2005). However the participants did not feel that this was necessarily appropriate when patients were dying. They appeared unaware of the two main arguments in the literature for the involvement of palliative care nurses in the assessment of risk for predisposition to disease: that palliative care could be the last opportunity to obtain a full family history of disease prior to the death of an older member of the family (Lalloo et al 2000), and that it can be the last opportunity for a generation for a blood sample to be taken to be used for predictive genetic testing (Kirk 2004a). Rather they felt it was more appropriate that the issues were raised at an earlier stage in the illness trajectory.

### ***Supporting Concerned Families***

Although the nurse-participants did not think it was appropriate that they identified patients who might benefit from genetic services and information, they did feel that intervention would be appropriate within palliative care if the patient or family themselves raised concerns about the potential risk of inherited genetic predisposition to disease.



*But yes I would see a place ... within palliative care, advising the rest of the family: if they ask for it and if they do ask about genetics, yes I feel we could support that and encourage it (NP1)*

*And if it is happening within that family at that given time and it is within this place: then it can, or could be dealt with in some way (NP6)*

*It would be difficult ... because there would be all those issues about approaching death but ... if it hadn't been raised with them before, it might be wrong not to, if you thought they might be at risk. It could affect peoples' lives (NP2)*

That is, they thought that it would be wrong to ignore the issue of inherited genetic predisposition if it was actively causing distress to the family. However, none of the nurses felt that they had an adequate knowledge base to properly support a patient and family who were worried about this issue. They consistently expressed a need for more education and training to feel confident about providing care to families who were worried about their susceptibility to cancer.

*We wouldn't have that in-depth knowledge.... We would need increased training obviously (NP4)*

*At the moment I don't really know how things are worked out, Genetics, who knows what it brings up (NP8)*

*It is quite a specialised area and I wouldn't feel informed. I wouldn't be able to do anymore than refer (NP3)*

Recognising the limitations of your genetics expertise is a key competency for nurses (Kirk et al 2003, Benjamin and Gamet 2005). The need to develop the educational provision for hospice nurses has been identified as a priority to enable nurses to support dying patients with a genetic prediction to disease (Clifford et al 2007). The nurses in this study all thought that their main (and perhaps only) role would be to enable patients to access appropriate expert advice:

*I mean I don't know a lot about it, but I could find out more. As with all questions that I am asked by families I will find it for them, or I will tell them where to find it (NP1)*

*If a family member raised a question and you were able to point them in the right direction. But I don't feel I could do anymore than point them in the right direction (NP3)*

*I'd let them talk but I'd say there would be a number of things which I wouldn't know how to answer. I'd get a man who knows (NP8)*

Seeking assistance from and referring to appropriate genetics specialists is the recommended practice for nurses when there is concern about a family history of cancer (Kirk 2004, Gaff 2005). However only three participants stated that they had been asked about this: two stated that they had referred the family to their general practitioner. (See also exemplar case three below).

*But I have had people ask me about the genetic link ... So I just give them advice that they should go to their GP (NP1)*

This advice fits with the advice in the government white paper 'Our Inheritance, Our Health' (DH 2003) that general practitioners should be the key primary health care professionals involved in predictive genetic medicine. Nevertheless it also emphasises that the nurses did not perceive the issue of genetic predisposition to disease as being part of their role. Nurses are encouraged to use their listening and advocacy skills to support families both before and after the referral process (Gaff 2005). It would be, for instance, virtually inconceivable that the same nurses would merely have suggested that the patients contact the GP about concerns related to symptom control, or psychosocial concerns about the dying process, although the GP remains the healthcare professional in charge of a community patient's care during their terminal phase.

### ***Clinical Practice: The Family Tree***

The genogram, or family tree, has been widely promoted within palliative care to encourage family-orientated care (Loissi et al 1997). It is a tool that helps piece together the family dynamics to consider what support is available to the patient and family (Hockley 2000), including spiritual resources (Cobb 2007). The hospice assessment procedure included a family tree which was used to assess the patient's and family's ability to cope with the impending death within the family.

*I do a family tree. ... I don't necessarily ask whether anybody else in the family has died of cancer, although it does generally come up then. But I will ask whether there have been any major losses really. What we are looking at is how they have coped with it ... We are really looking for the impact of the illness on the family and how they have coped with it (NP1)*

*To see if there are any dependants, to see what their support network is really. The ones I worry about are the ones where there is nobody around. I really worry about those. And then the big ones, with lots of people: they are probably fairly lively (NP7)*

*I always personally look at the family tree just to look at where we are. To see if parents are alive, to see how many children there are, and what the dynamics are really (NP3)*

Hence the purpose of the family tree was very different to its use in clinical genetics where the aim is to document the family history of cancer as accurately as possible (Skirton et al 2005). All the nurses were aware of this distinction. They were also all aware that an inherited susceptibility to cancer was associated with a pattern of multiple occurrences of the same or related cancers within families. However, none of the participants felt confident about completing a pedigree analysis or assessing risk of inherited disease from the distribution of cancer within a family.

*Sometimes it can seem that there is a lot of it, but it is just a kind of co-incidence. ... there had to be several people in the same family and that it had to be the same tumour and things like that from the research. And sometimes it just isn't hereditary but sometimes it is (NP2)*

They were also aware that inherited susceptibility was more common in some cancers than others. The most commonly mentioned breast and colon cancers, the two most common cancers for which genetic testing is possible.

*There is definitely a genetic link with breast and ovarian cancer, and bowel cancer (NP1)*

*I mean there are certain types of cancer that you tend to think are more particularly linked, for instance breast cancer ... Some of the more gynae related cancers as well (NP9)*

Hence they were aware that pedigree analysis was a complex task and had a different purpose from compiling a family tree, and that the high incidence of cancer in Britain meant that it was not easy to distinguish between an inherited predisposition to cancer and other causes for familial clusters (Skirton et al 2005). Although the nurses felt competent to use the family tree as a tool to assess the psychosocial needs of families, they did not feel equipped as regards its use for recording the family pedigree.

### ***Clinical Practice: Patient Care***

Only half the nurses had knowingly nursed a patient with a family history of cancer that they knew or presumed was associated with an inherited genetic predisposition to cancer. Some of these examples concerned patients whose concerns had been dealt with prior to their referral to palliative care services.

*I seem to remember one family. I seem to remember that they were already under the care of the hospital for that (NP8)*

These experiences do not seem to have presented any special concerns for nursing care. They were, however, more aware of the issues for families with other diseases that were more closely associated with a genetic predisposition to disease

*Huntingdon's disease: Her brother had it: he died of it. And she has Huntingdon's and she is alive currently ... because there is a lot of worry going on in the patients' mind and the families' mind as well ... more than with cancer ... certainly with Huntingdon's there has been this sort of feeling that, will I get it next? (NP8).*

These two quotes, both given by the same nurse, highlight a paradox of the nursing data which is that the nursing staff were aware that inherited genetic disease could provoke specific concerns in relatives with the potential to develop the disease. They were also aware that these relatives might need extra support because they were worried that they might develop the disease in the future, but they did not perceive this as a concern for patients and families with cancer, even (as above) for patients and families who were already identified as having an increased risk of an inherited genetic predisposition.

None of the nurses in this study mentioned that they had participated in the care of any patient where any member of the hospice multidisciplinary care team had initiated action that led to any changes in care due to the potential of an inherited predisposition to cancer. That is, what was most notable about the nurses' data is that any issues associated with potential future disease were not prioritised in any of the given examples. The need to identify clients who may benefit from genetics services (Kirk et al 2003, Gaff 2005) was missing from their agenda.

This is illustrated using exemplar cases from the nursing data. They are used to illustrate different scenarios where a potential genetic predisposition to cancer had impacted upon the care needs of palliative care patients and their families. They were selected (from a small pool of data) as they were especially representative cases (Miles and Huberman 1994) that illustrate the reasons for, and potential consequences of inaction, around issues of a genetic predisposition to cancer within a palliative care setting.

### Exemplar-Case One

The first exemplar-case illustrates a scenario where concerns about the future risk to (adult?) children were recalled as one of the main psychosocial concerns of the dying patient.

*I mean his mum died of it, and her mum had died of it and her brother had died of it. So it was known to be in the family. So she was worried about her son and daughter (NP3)*

*Did that bring up any different issues for you? (I)*

*No, and I think because the family weren't in this country. ... The son and the daughter were abroad. So, perhaps I didn't think about it any further because I didn't have to (NP3)*

Genetic counselling is not a necessity for every patient whose disease might have a heritable component (Frazier et al 2004). Any nurse educated in genetics can use their knowledge to identify and differentiate risks, and refer to specialists when appropriate (Frazier et al 2004). Systematically collecting information about three generations or more can help clarify risk, and contacting a specialist service with this information can help clarify when referral to a specialist service is appropriate (Gaff 2005).

In this exemplar case no proactive actions were taken and the patient died with worries for her children. However, as disease that occurs in the paternal family has no genetic association with disease that occurs in the maternal family (Gaff 2005), a simple knowledge of genetics would have enabled the nurse to explain why the incidence of cancer in the patient's bloodline needed to be considered separately from the cancer in her husband's family, when considering the risk to their children.

Ensuring that questions are systematically asked about other first and second degree blood relatives, who have not developed cancer, can also help clarify risk. With this knowledge the nurse could have asked pertinent questions about the patient's siblings and maternal aunts and uncles, including questions about age at first diagnosis to see whether the patient's family history of cancer warranted referral to the regional clinical

genetic unit (WMFACS 2007 Referral guidelines: see appendix One). This would have clarified whether the patients concern required actioning and perhaps reassured her that her concerns were being taken seriously.

Similarly, there did not seem to be any awareness about the possible actions that could have been taken to enable the patient's children to access health promotion measures if they were at increased risk of developing disease. It may have been the last opportunity for them to learn about their family's history of cancer from their mother (Lalloo et al 2000). It is also possible to consider genetic testing or blood banking within a palliative setting (Kirk 2004a). This allows other family members to be tested for the particular genetic alteration that occurs within the family. This may have reassured the patient that she could do something active to support her children if they were at risk, as people with cancer can be pleased to act altruistically and help other family members assess their own risk of disease (Hallowell et al 2004). This would, however, have been complex in this case as the children were overseas, as clear arrangements need to be in place as to who will be given the test results after a patient has died (Kirk 2004a).

### Exemplar-Case Two

This case highlights a scenario where the risk of an inherited predisposition to cancer had been identified but it was decided that palliative care was an inappropriate setting for risk assessment:

*The mother died here in the summer. The two daughters have breast cancer. One was very poorly from the minute the mum died ... And she has just been diagnosed with ovarian cancer ... And the other sister has got bone secondary's (NP7)*

The nurse was fully aware that the family history of disease could be associated with an inherited predisposition to cancer and the increased risk that the children/grandchildren had of developing future disease, as she continued:

*... because what we have to do is look at the eighteen year old (grand)daughters that these two women have as well and think about counselling for them but they just aren't ready for that so we are holding back on that. Because they just couldn't cope with the set back at the moment. And we are just trying to gently try to support and counsel them and then hopefully move onto that at a later date (NP7)*

Concurrent occurrence of cancer in more than one member of the family can cause intense grief (Kissane and Bloch 2002). It is a situation where even well-functioning families may require professional support to sustain their wherewithal to cope (Kissane and Bloch 2002). Genetic information has the ability to disturb further the ties that constitute the family structure (Mallet and Chekroun 2001). The judgement that '*they just couldn't cope*' did not appear to have been made lightly in this scenario.

Communication in palliative care can be very complex as feelings of grief and loss can be hard for patients with incurable disease to express (De Haes and Teunissen 2005). This scenario highlights the disadvantage of leaving conversations about the risk of inherited disease until patients are dying. The experience of advanced progressive disease and the realisation of impending death can, in and of themselves, present patients and families with multiple psychosocial challenges (Vachon 2005a,b, Panke and Ferrell 2005). The juxtaposition of these fears with the additional stresses caused by the risk of potential future disease was perceived as too much in this instance.

Unfortunately the phrase '*and then hopefully move on to that at a later date*' (NP7) does not suggest that careful consideration had been given to where or when it might be appropriate to raise the issue of inherited disease. This is important because open awareness, a condition marked by knowledge of impending death and a value commitment to openness has led to increased satisfaction in the care of the dying



(Searle et al 1997). Glaser and Strauss's (1965) seminal work on the awareness of dying documented how different states of awareness in patients could alter the way that an individual coped with the dying process. They described the way that 'closed awareness', where health care professionals were aware that a patient was dying could lead to 'suspicion awareness' in the patient. In this state the patient suspects he is dying and is trying to verify this with professionals. This may develop into 'mutual pretence' where both staff and patient know about death but pretend otherwise. They documented how open awareness increased the ability to achieve the management of an acceptable dying process (Glaser and Strauss 1965).

Exemplar-case two appeared to document closed awareness about inherited susceptibility to disease. However it is possible that awareness suspicion of genetic predisposition to cancer was contributing to the patient's and family's stress. Media coverage of the breast cancer genes has been widespread and has been shown to cause spontaneous discussion and debate (Henderson and Kitzinger 1999). Chalmers et al (2003) found that the need for information about the personal risk of breast cancer was the topic most frequently identified as being very important in sisters and daughters of women with breast cancer. This study also revealed that several of the patient-participants had concerns about inherited disease that they had that not discussed with healthcare professionals (See p155). These concerns were emotionally charged for one patient.

In the communication between patients and healthcare professionals both parties have an active role in shaping and constructing encounters (Payne 2002). Prior expectation of role can affect how patients communicate with healthcare professionals (Jarrett and Payne 1995, Jarrett et al 1999), and the patients in this study did not appear to think that it was important to discuss their family history with palliative care nurses.

Nurses can also block communication about difficult patient concerns and worries (Wilkinson 1991), and no nurse in this study felt confident at dealing with this issue.

Daly et al (2001) suggest that Buckman's (1992) six step strategy for breaking bad news can be adapted for discussion about an inherited genetic predisposition to cancer. These steps are 1) Getting started, 2) Finding out how much is known, 3) Finding out how much they want to know, 4) Sharing the information, 5) Responding to feelings and 6) Planning and follow-through. Even completing the first two steps, setting aside time for a discussion in an appropriate place with the appropriate people and then asking open questions to find out whether there are any concerns that relate to the family history, may potentially open up concerns about inherited disease (Daly et al 2001, Buckman 1992). This would ensure that awareness suspicion or mutual pretence (Glaser and Strauss 1965) were not an issue and not contributing to patient and family distress.

Exemplar-case two was not the only scenario described where nurse-participants commented that they had deliberately decided not to raise the issue of inherited susceptibility to disease.

*I can remember a lady who had bowel cancer and she had other members of the family who had died of bowel cancer... because she had a son and a daughter... but we didn't discuss, it wasn't appropriate ... She struggled with emotional issues, which were more important at the time than that (NP3)*

Hence other emotional issues associated with advancing incurable disease were again seen as being more important than raising new concerns about inherited predisposition. These emotional concerns acted as a barrier to communication about familial disease.

### Exemplar-Case Three

The third exemplar-case documents a scenario where relatives returned to the hospice to enquire about their risk of inheriting cancer following the death of their mother.

*But I do remember there were two ... sisters who were grown up. ... They came back here to ask about themselves ... and I just came to talk to them and their fear: Was it hereditary? ... It was either their mother or their sister who had died here and then their grandmother had had it as well. So I thought well, there is something here ... we sent them onto special clinics: breast (NP5)*

The nurse had appropriately referred the relatives to the regional clinical genetics service (DH 2003). However, she did not appear to have any awareness that the relatives' ability to ascertain their individual risk of developing breast and/or ovarian cancer could be affected by whether the issue was raised before or after the deaths within the family (Lalloo et al 2000, Kirk 2004a). A death within a family, especially the death of a parent, can alter family communication patterns (Foster et al 2004, Kenan et al 2004) and ability to learn about cancer within the family. The participant also appeared unaware of the need for a blood sample from an affected relative to enable other relatives to be tested for the specific familial genetic alteration (Kirk 2004a). Hence the relatives in this exemplar-case may have missed the last opportunity for this to occur until one of them (potentially) develops the disease in the future.

The nurse remembered exemplar-case three because of the emotional content of the discussion that she had had with the patient's (adult) children.

*... I remember the thing that came across was fear. They were fearful and one of them said that they wanted to have a mastectomy. Yes, I remember that because it did strike me: I thought 'God, I would never have a mastectomy' ... so they were very afraid (NP5)*

Although these fears were strong enough to provoke these relatives into action following their mother's death, they do not appear to have been recognised by hospice

staff or raised by relatives before the patient's death. The fear and anxiety mentioned perhaps hint at how distressing it can be for a relative to watch the death of a family member wondering, if they might be going to develop and die from the same disease yet feeling unable to discuss it. It hints at the stress for relatives that can occur when they have an awareness suspicion (Glaser and Strauss 1965) of genetic disease but were unable to discuss it as their mother was dying.

This does not mean that it would always be helpful to introduce the topic of inherited disease in a complex scenario due to the potential to cause undue emotional distress (see exemplar case two above). However, this exemplar-case demonstrates the potential emotional and practical cost to families when patients and families do not have opportunity to express any concerns they have about their family history of disease before death.

#### Comparison of Exemplar-Cases Four and Five

The following cases were described by one nurse to highlight the rewards, strengths and benefits of continuity of caring for families when multiple deaths occurred over time.

*My initial contact was with a lady in her eighties ... I think it was bowel cancer. She died very nicely at home. All the family were very involved ... The following year her son got a brain tumour and died. Not many years after, her husband ... got cancer. I can't remember where, but he died. And again I was very much involved with each member of the family. I still get Christmas cards and such things (NP1)*

*I met ... a woman in her forties, who died of bowel cancer at home. She was looked after by a very supportive family consisting of mother and father, husband and two children. And not very long afterwards her mother got bowel cancer and died at home supported by her husband. The son-in-law died (Not cancer) ... quite suddenly. And I have been in contact with the father of the whole family, the granddad to the girls ... since really (NP1)*

The nurse used these examples to highlight how knowing a family previously could benefit care:

*And then it is actually nice because I know the family set up. I know what actual support is going to be there. I know that it will be great because I have already experienced it with the other members of the family. We're friends; we do become friends with many of the families that we visit. It is a real privilege to visit somebody at home (NPI)*

However, comparing the two cases demonstrates how the psychosocial care of the patient and family was given without regard to the potential for an inherited genetic predisposition to cancer.

In the first scenario the nurse participated in the care of three family members with different cancers. As discussed above the disease that occurs in the paternal bloodline has no genetic association with the disease in the maternal bloodline (Gaff 2005). In this instance, the deaths of three family members from different cancers, two of which occurred when patients were in their eighties, suggest a sporadic rather than an inherited susceptibility to disease (WMFACS 2007: See Appendix 1). Although only two family members died from cancer in the second scenario, the fact that they both had the same cancer, which is known to be associated with an inherited predisposition to disease, and that one of the deceased was in their forties meant that they met the referral criteria to the regional clinical genetic specialist clinic (WMFACS 2007). The expert psychosocial care the family had received is evidenced by the fact that the nurse was contacted by the grandfather as he tried to support his grandchildren following the sudden death of their second parent. The lack of awareness about the potential risk of an inherited genetic predisposition to effect care is underlined by the fact that the nurse did not appear to recognise the different genetic implications apparent within the two exemplar cases. In exemplar-case five the lack of attention given to familial disease did not seem to be explained by the need to focus on other priorities around the time of

death: rather it suggested that the nursing care was being given within a paradigm (Kuhn 1996) that did not consider the implications of genetic predisposition to cancer.

### ***Patients' Perception of Nursing Care***

The information presented above documents how the nurse-participants felt that they did not have the appropriate knowledge or skills to support families who were concerned about their family history of cancer and the potential for an inherited predisposition to disease. The exemplar-cases demonstrate how this affected patient care. However, it was noteworthy that the nurse-participants' anxieties about caring for families with a family history of cancer in the context of genetic predisposition were not reflected in the patient-participants' comments about the care that they and their families had received. The patient-participants all praised the standards of care at the participating hospice.

*They do more or less go double-jointed here to help. Anybody who wants to fault these nurses here, they need a good sledge-hammering across their head (Iain)*

*I must admit coming to the hospice is really good thing, coming to the hospice has really helped me a lot (Finlay)*

*Cause the care that they give me from the hospice is wonderful (Grace)*

*I must say the staff are very, very good (Harry)*

*Because everybody has been good to me: It's absolutely wonderful, absolutely wonderful place. Opened my eyes you know (Keith)*

All the patients spontaneously commented on the nursing care that they had received from the hospice. It was universally praised and most commonly described as wonderful. The high standard of care received was frequently favourably compared to the care received by other services during their cancer journey.

## **Discussion**

This chapter is called ‘The Missing Agenda’ to draw attention to the way that the nurse-participants did not appear to recognise the potential for an inherited predisposition to cancer to affect the care needs of palliative care patients. This is important as all health care professionals are expected to be confident and effective when dealing with patients with an inherited susceptibility to disease (DH 2003, Kirk 2004b). To understand these findings it is important to consider the nature of nursing and how nurses develop their expertise. A seminal model that examines this is Benner’s (1984) ‘Model of Skills Acquisition’.

### **Benner (1984) Model of Skill Acquisition**

Benner (1984) suggested that expert clinical nursing relies both on theoretical and practical expertise that is gained through experience. That clinical acumen consists of practical knowledge and skills (knowing how) as well as consideration of the underlying theoretical knowledge base (knowing that). In her phenomenological work ‘*From Novice to Expert*’ Benner (1984) used the Dreyfus model of skills acquisition (1980) to model how nurses develop their practice.

Benner (1984) described a five stage process of increasing competency whereby nurses developed from novice, through advanced beginner, competent, proficient to expert. Each step is built on previous clinical learning. Novices have no experience of situations in which they are expected to perform. As they have no experience they require rules to guide their performance; however, following inflexible rules legislates against successful performance because the inflexibility and narrowness of rule-based

behaviour negates the individualised response required to respond to a particular patient's needs (Benner 1984).

Competent nurses are characterised by their conscious, deliberate planning of care in the context of long term goals. This enables them to prioritise and manage the many contingencies of clinical nursing. Developing through advanced beginner to competency takes time, typically years, but all nurses are expected to develop competency (Benner 1984). With experience some nurses will progress through proficiency to expert, when the nurse no longer relies on analytical principles to connect their understanding of a situation to an appropriate action but is able to respond intuitively and appropriately to patient need (Benner 1984).

Benner's (1984) model of skills acquisition has been enormously influential especially in the field of nurse education (English 1993, Field 2004). However, the way that the findings of single phenomenological study with critical care nurses has been transferred into other settings have been criticised (Altmann 2001). It has also been suggested that it promoted an uncritical development of a reflexive approach to nurse education (Field 2004), and that describing expert clinical judgement solely in terms of intuition is inappropriate (English 1993). Nevertheless it has provided insight into nursing and provides a valuable model for nurse education and practice.

#### Evaluation of Findings with regard to Benner's (1984) Model of Skills Acquisition

The findings from this study suggest that nurses who were expert (Benner 1984) at giving care outwith the genetic paradigm were novice (Benner 1984) at giving care within the genetic paradigm. This has profound implications for palliative care, because it suggests that if palliative care nurses wish to improve their care for families with a family history of cancer, they may not only have to develop their knowledge base but



change the paradigm within which they work: that is, to give care through the genetic lens (Kirk 2004b). Different paradigms cause different facts to have different significance (Kuhn 1996), and concerns about future occurrences of cancer perhaps seem much less significant when the focus of care is on ‘the active care of patients with advanced progressive disease’ (NCPC [www.ncpc.org.uk](http://www.ncpc.org.uk) accessed 16/8/07) than when seen through the lens of cancer genetics and realising the potential of genetic information for health (DH 2003).

Changing the paradigm within which people work can frequently cause confusion and even distress to individuals until the implications of the new paradigm are assimilated (Kuhn 1996). Novice care is defined as care by nurses who have no experience of the situations in which they are expected to perform (Benner 1984). Even expert nurses become novices when faced with new practice scenarios (Benner et al 1994). Findings suggest that giving expert care to patients and families is different when ‘family’ is defined as blood relatives who may have a inherited predisposition to cancer, as opposed to the broader definition of family that includes caregivers and those who have strong emotional and societal ties to the patient, which is common in palliative care (NICE 2004).

The exemplar cases show that there was a discernable affect on patient care when experienced palliative care nurses were practising in scenarios where they had no prior experience, without a clear understanding of the knowledge or skills required to support patients. In exemplar-case one the risk of inherited disease was not prioritised even when it was acknowledged to be of major concern to the patient. Benner (1984) suggests that ‘the heart of the difficulty lies in the fact that since novices have no experience of a situation they face; they must be given rules to guide their performance. But following rules legislates against successful performance because the rules cannot

tell them the most relevant tasks to perform in an actual situation' (Benner 1984). That is, a set of guidelines or instructions alone is not adequate, and a novice needs experience before guidelines can be applied to individual patients (Benner 1984).

It is easy to understand that nurses who were novice in providing care through the genetics lens might hesitate to starting looking at patients' family's histories and related communication issues within a framework of genetic disease. Nevertheless, knowledge about genetic predisposition to disease offers new hope to families as it aims to identify individuals who are at increased risk of developing cancer and ensure that they are able to access health promotion measures and early treatment that is associated with improved treatment outcomes and lower morbidity rates in cancer (Sadler et al 2004, Rieger 2004, Bell 2004). That is, the aim is to try to prevent multiple, young deaths occurring in families and the attendant stressors on families that were highlighted in previous chapters.

To progress from being novice, nurses need both experience and role modelling from expert practitioners who have a vision of what it is possible to achieve within a given situation. Benner's (1984) model of nurses progressing from novice to expert suggests that an improved knowledge base alone will not automatically improve practice, rather nurses also need to develop a practical knowledge that is embedded in clinical expertise. In this study the nurses readily acknowledged their lack of knowledge about genetics but they did not appear to be able to visualise expert practice. This is often learnt through role modelling (Benner 1984), and there were no experienced role models available in this setting. This left the nurses unaware that the present model of care for families with a family history of cancer was not considering all aspects of the patient experience: the link between their family history of cancer and the risk of a genetic predisposition was missing from their agenda. As they did not

appear to fully perceive the specific care needs of this patient group, they were unable to act on them. This suggests that the nurses not only needed an increased knowledge base about the multifactorial aetiology of cancer but also an increased vision of the possibilities of care (Benner 1984) in families with a family history of cancer.

Findings further suggest that it is inadvisable to leave discussions about inherited susceptibility to cancer until the disease becomes advanced and incurable. The nurse-participants gave cogent and reasoned arguments to support this view. There were two key concerns that were repeatedly raised about discussing genetic predisposition to cancer within a palliative care context. These were:

- The imminence of death
- Clinical genetics was a separate speciality

The imminence of death was the major factor when the nurses considered the appropriateness of dealing with issues related to genetic predisposition to cancer. Communication at the end of life is frequently complicated by the practical, emotional, spiritual and emotional issues that can attend the dying process (De Haes et al 2005). Several participants felt it was too late in the patient's journey as they were aware that the dying person themselves would not benefit. They were also concerned that it might deflect the focus of care away from the dying patient onto the family, and felt that the imminence of death could mean that families associated an inherited susceptibility to disease with death rather than seeing it as an opportunity to take health promoting action. Exemplar-case two highlighted the complexity of psychosocial concerns that could attend deaths in families with a family history of cancer. Some nurses reported deliberately choosing not to have open discussions about the family history of cancer as they worried about increasing stress in an already distressed family. They felt it was 'too much too late' in the patient journey.

Despite this strong feeling that the issues about inherited susceptibility to cancer would be better dealt with before the palliative stage, the findings from this study show that in practice patients were dying without these needs being appropriately identified or met. The nurses freely and consistently acknowledged that their understanding of cancer genetics was limited. This indicates that improved knowledge and training for palliative care nurses is a priority if they are to give appropriate care to patients who are worried about their family history of cancer. Education in genetics has previously been documented as a priority for palliative care education (Clifford et al 2007).

However Benner's (1984) model of nursing development suggests that an increased knowledge base alone may not be enough to improve practice and that a new bridge between practice and education may need to be developed (Dolan 1984). Clinical knowledge and skills are learnt through time, experience and from role models. Consequently novice palliative care nurses may need role modelling from practitioners who are experienced in giving care to people who are concerned about inherited disease. Achieving this would require more time, imagination and money than merely providing didactic information. It might be achieved in innovative ways: by forging links with a specialist genetics unit, with joint visits to community patients, genetic nurses attending the hospice for ward rounds with specific patients, or even palliative care nurses shadowing genetic nurses for a period of time.

These findings reinforce the idea that nursing care is reliant on knowledge being embedded in practice (Benner 1984). 'Any nurse entering a clinical setting where she or he has no experience with the patient population will be limited to the novice level of performance if the goals and tools of patient care are unfamiliar' (Benner 1984: 21). This does not impugn their ability to give competent or expert care within their areas of expertise, as documented by the patient-participants consistent and unsolicited praise

for the nursing received in the participating hospice. It is, perhaps, unsurprising that these nurses were novice at caring through the genetics lens as the knowledge about inherited predisposition to cancer is a new and rapidly changing area of knowledge (Bell 2004). Thus, there had been little time and/or recognised relevant scenarios through which nursing staff could develop their clinical competence.

One very important finding, which should be emphasised in all the data presented, is that all the nurses that participated in this study freely and openly acknowledged their lack of knowledge about caring for families with concerns about inherited disease. In the conscious competence learning model variously attributed to Confucius, Socrates or an Unknown Persian Philosopher (see opening epigram) and several more recent authors, being consciously incompetent is the second key stage in learning. It leads to the commitment necessary to learn new the skills and abilities needed to achieve a task. Consequently, in being aware of their need to learn more, and in their ability to articulate their concerns, these nurses may have started the process of becoming competent practitioners when caring for patients with a family history of cancer.

## **Conclusion**

This chapter has presented the nurse-participants' insights into caring for patients who are concerned about inherited disease within a palliative care setting. It highlights their reservations about the appropriateness of raising the issue of genetic predisposition to cancer in the context of advanced progressive disease. It suggests that the nurses were novice at caring for patients and families within the genetics lens and documents how this affected patient care.

Limited understandings of the contextual meaning of facts in areas where the goals and tools of patient care are unfamiliar define novice care (Benner 1984). As indicated on p1, this study was provoked by a similar novice response to the complex care

requirements of relatives who were concerned about their family history of cancer. Kirk (2004a), Lalloo et al (2000), Mallet and Chekroud (2001) document how concerns about inherited susceptibility are impacting the care needs of palliative care patients. Ten percent of Clifford et al's (2007) extensive survey of palliative care nurses had encountered issues associated with inherited diseases, including cancer. This suggests that concerns about inherited disease are a real, present issue within palliative care. The nurse-participants' novice practice suggest that it is a missing agenda within palliative care.

However, the need for clinical genetics to become a mainstream component of the medical treatment of cancer is becoming increasingly apparent (Bell 2004). The demand for earlier and more accurate prediction and diagnosis of disease, alongside new pharmacogenetic treatments, will promote its integration into care. This move to clinical practice may be slow but it appears to be inevitable (Bell 2004). As between five and ten percent of all cancers are thought to be associated with inherited disease (Claus et al 1991) it is possible many more patients will become alert to the psychosocial issues linked with inherited susceptibility to disease. This challenges nurses to develop their competence 'to be fit for practice in the genetics era' (Kirk et al 2003). This is discussed further in the next chapter.

## CHAPTER TEN: THE MISSING DISCOURSE

(Discussion and Implications for Practice)

*To genetic evolution, the human lineage has added the practical track of cultural evolution (Edward O. Wilson 1929)*

### Introduction

This study provides insight into a complex phenomenon; the meaning of a family history of cancer, at a time when the understanding of the phenomenon is changing. This chapter describes how the family history of cancer is presently a missing discourse within palliative care. A discourse is ‘the spoken or written treatment of a subject in which it is handled or discussed at length’ (OED online accessed 7/9/08), and it is argued that more attention needs to be paid to the concerns of patients with a family history of cancer because of the potential for this to be linked with an inherited genetic predisposition to cancer.

This chapter discusses the information that emerged from the study from two different interpretive perspectives: from ‘outwith’ and ‘within’ a genetics paradigm. It draws attention to the way that different factors, like multiple occurrences of cancer in the family, multiple primary cancers, and individuals within the family developing cancer at a younger age than normal, have different significance depending on the worldview taken. It is proposed that a new model of care is required to provide appropriate support for families with a family history of cancer in the context of genetic predisposition to disease. Finally it highlights two barriers to the implementation of change. These are a) the poor understanding of cancer as a multifactorial disease and b) the novice practice of nurses with regard to caring for families where there is the potential for genetic susceptibility disease.

Although it has been suggested that researchers using a phenomenological approach should refrain from engaging with previous research literature to avoid being influenced by preconceptions, research needs to be informed by what is already known about a phenomenon (Todres and Holloway 2006). As discussed (p28) there has been very little research into the effect of a family history of cancer on palliative care patients. Hence the findings are considered in the light of the existing knowledge about the psychosocial effect of a family history of cancer and/or an inherited predisposition to cancer at any stage of the cancer journey. This literature is also limited (Hallowell et al 2004), so research that examines the experiences of individuals with a family history of cancer and have attended genetic counselling (and undergone predictive genetic testing), has also been used, especially papers where the earlier deaths of other family members are discussed. Papers which informed this discussion are shown in Table Eight.

**Table 8: Research papers that contribute to discussion**

<b>Author</b>	<b>Aims</b>	<b>Methods/ Analysis</b>	<b>Participants Sampling Strategy</b>	<b>Death Dying theme</b>	<b>Findings And Implications</b>
Arman et al (2006)	To understand women's beliefs about the genesis of their breast cancer	Semi structured interviews	59 consecutive admissions from an anthropological hospital with 59 matched patients from a general hospital  Sweden	No	Three themes emerged 1) belief in a link to life lived 2) Heredity as sole genesis 3) Rejection of the question
Bonadona et al (2002)	To evaluate the consequences of disclosure of a positive genetic test result to people with cancer	23 Structured interviews,  Questionnaires,  Psychological assessment scales	All clients with cancer who agreed to a retrospective interview following genetic testing between 1994-1999 at one clinic  France	Yes But of Patients in remission	Although patients did not regret testing a significant number were distressed by test result, found difficulty discussing this with relatives. Concerned about their own risk of developing future disease.
Esplen et al (2007)	Cohort study of colorectal cancer survivors with a	319 colorectal cancer patients	Recruitment from a population based cancer	No	Concern for children's future health was the most frequently given



	family history of cancer who were undergoing genetic testing	Validated questionnaires	registry Canada		reason for undergoing testing
Forrest-Keenan et al (2005)	To explore the barriers and facilitators in family communication about genetic risk	56 Semi-structured interviews (29 HD & 27 HBOC)  Grounded theory	All clients recruited from one genetics clinic  Scotland	No: but death mentioned as affecting all three themes that emerged from the data	Communication about genetic risk complex: dependant upon individual familial and cultural histories
Foster et al (2004)	To explore how families communicate about their potentially increased risk of disease	Participants interviewed pre & six months post predictive genetic testing	15 healthy women attending for predictive genetic testing for cancer  UK	No: but death mentioned as affecting five of the seven themes that emerged from the data	Women faced numerous dilemmas when deciding whether or not to discuss testing with family
Hallowell (1999)	To understand how woman attending a genetics clinic perceived risk and risk management options	46 Semi-structured interview  Thematic analysis	All clients visiting a genetic clinic over a year Excluded People with cancer & the recently bereaved  UK	Yes	Obligation to dead had motivated some clients to attend but motivation to living relatives more important
Hallowell et al (2004)	To explore the relationship between risk and uncertainty in people with cancer who underwent genetic testing	30 Semi-structured interview  Thematic analysis	All clients with cancer who agreed to a retrospective interview following genetic testing between 1994-1995 at one clinic  UK	No But future concern	Most participants had integrated the risk of cancer re-occurrence into their self identity and generally to comfort in being able to assist other family members evaluate their health risk
Kenen et al (2004)	To explore how family communication patterns influence the dissemination of genetic information	Semi – structured interviews  Participant observation (in genetic clinic)	21 healthy women who were the first members of their family to be tested (or who were unaware of other family members who had been tested) for breast cancer UK	No: but noted that previous deaths within family affected family communication pattern in different ways	Identified different communication patterns <ul style="list-style-type: none"> <li>• Open</li> <li>• Blocked</li> <li>• Indirectly blocked</li> <li>• Self-censored</li> <li>• Third party</li> </ul>
Walter et al (2004)	Systematic review & synthesis of the qualitative literature about understanding of risk of familial disease	Systematic Literature Review	11 original research based articles reviewed  UK	No	Sense of vulnerability informed by <ul style="list-style-type: none"> <li>a) Salience of family history</li> <li>b) their personal model of disease causation and inheritance</li> </ul>
Wold et al (2005)	To describe cancer survivors beliefs about breast, colorectal and prostate cancer	Survey of 670 cancer survivors	Participants from a register of patients and relatives to support research in cancer causation. USA	No	Cancer survivors beliefs about cancer causation are substantially different than those of experts

### **A Missing Discourse: ‘Outwith the Genetics Paradigm’**

This section considers the model of care identified in this study. It shows that consideration of the family history of cancer is presently ‘A Missing Discourse’ within palliative care.

The first key finding was that the patient-participants’ experiences had been significantly affected by the deaths of first degree blood relatives who died at a younger age than normal, as this had altered their family cohesion and communication structures. Several participants also noted the way that previous deaths of younger relatives (especially parental death in childhood), affected the social and emotional support that they were receiving from their families. The nurses also drew attention to the needs of families where an adult was dying at a younger age than normal. They described how caring could become more complex, as patients and families had to redefine their relationships and expectations of one another when a family member died at a younger age than anticipated. Despite the pattern of early deaths, none of the nurse-participant and only one patient-participant (Diane) related the age at death, (or the age of first developing cancer), with the increased likelihood of an inherited genetic predisposition to cancer within families.

The second finding was that the family history of cancer could have a range of effects on patients’ emotional needs. This varied from patients who reported no impact on their present circumstances to overwhelming emotional distress associated with the deaths of previous family members. However the most commonly noted impact was an increased awareness of the dying process. This had the potential to affect quality of life for patients. It both equipped them with knowledge about the dying process and heightened the emotional significance of particular milestones in the cancer journey. The nurse-participants described the way they regularly spent time with patients,

listening and responding to concerns provoked by particular deaths within the family. They also described scenarios where they had liaised with the multidisciplinary team to support patients who were overwhelmed by emotional distress due to previous deaths within the family. However the focus of care was on providing emotional and social support for families and the assessment of family history of cancer was not considered.

Describing the family history of cancer as ‘a missing discourse’ is not meant to imply that individual needs and concerns that might be associated with their family history of cancer were not being met: rather that they were being attended to within different discourses. For instance, there is widespread awareness that dying at a younger age than anticipated can impact care needs (Willis et al 2001, Sheldon and Tribble 2004, MacPherson 2005, MacPherson and Emeleus 2007).

Care of the family is integral to the definition of palliative care (Twycross 2003). However the care of blood relatives appeared to be subsumed within the broader definition of ‘family’ that is widely used in the palliative care literature (as discussed p25). This includes caregivers and other people with strong societal, emotional and care-giving links to the patient (NICE 2004). Hence concerns about family communication and cohesion appear to have been subsumed into concerns about whether patients were being physically, emotionally and socially supported through the dying process, without particular reference to whether family (as defined in this study) were aware of the family history of cancer and any potential risk of genetic predisposition. This model of care aims to ensure that the patient, (defined as person with cancer), and those people who had strong emotional and social links with the patient (NICE 2004) are supported in the presence of advancing incurable disease.

### The Effect of Inherited Genetic Predisposition

An awareness of the potential for an inherited genetic predisposition was found in this study, however, and many participants were concerned that other family members might develop cancer in the future. The nurse-participants stated that patients who expressed concerns about the family history of cancer were referred to either their general practitioner (GP) or the regional specialist genetic service in accordance with the Department of Health guidelines (DH 2003). Hence these patients were receiving the same care as other patients, except that specific concerns about genetics were referred to an external expert.

Within the present model of care it is even questionable whether palliative care is an appropriate place to deal with these concerns. It has been stated that '*In the field of palliative care, we believe that the doctor should either abstain from discussions or proceed with considerable caution*' (Mallet and Chekroud 2001: 149). This is because these conversations can promote anxiety and family discord during the dying process, which may outweigh the benefits to other family members (Mallet and Chekroud 2001). The nurse-participants also felt that genetics was a separate speciality and that the imminence of death made discussion of genetic predisposition inappropriate in the circumstances.

This study adds to this debate. As discussed in Chapter Three it was designed to minimise the potential for emotional distress and the topic of genetic predisposition was not raised with patient-participants unless they themselves first introduced the topic. Despite this it uncovered significant and widespread concerns about familial disease. This suggests that it is possible to discuss these concerns using the appropriate communication skills. Buckman's (1992) six step strategy for breaking bad news has been adapted for this task (Daly et al 2001). Merely signalling interest about previous

deaths from cancer within the family may draw out concerns from patients, enabling open discussion about specific fears and circumstances. This would allow reassurance to be given about inappropriate concern and/or discussion about appropriate actions (like documenting the family history of disease and referral to genetic services) to occur. This may be a sensitive topic for patients, but no more so than many other issues associated with death and dying. (For instance, helping patients prepare their children for parental death).

The research interviews highlighted several disadvantages to leaving discussions about familial disease until cancer was at an advanced stage. The fact that Grace was unable to continue the interview due to her high symptom load, despite a strong desire to share her experiences, showed how physical symptoms could inhibit/prevent discussion about this topic (p71). The interview with Iain showed not only that the topic could provoke distress but also that there could be insufficient time to appropriately follow through concerns about inherited disease prior to death (p161). The nurse-participants universally felt that discussion of inherited disease should occur before cancer became incurable and concerns about imminent death and dying were of prime importance.

It is also noteworthy that the findings may suggest that the patient-participants did not view the participating hospice as the appropriate place to discuss these concerns. For instance, more participants had discussed their fears with other family members than with hospice staff. It is known that prior expectations of role can affect how patients communicate with healthcare professionals (Jarrett and Payne 1995, Jarrett et al 1999) and it may be that these participants did not view a hospice as the appropriate service to assist with this issue. This was perhaps realistic, as the nurse-participants clearly stated they felt cancer genetics was a separate speciality. They consistently said

that they did not have an adequate knowledge base to assess inherited risk, which is appropriate within this model of care where genetics and palliation are seen as separate specialities.

Hence the fact that this study showed that it was possible to discuss familial cancer within palliative care does not mean that conversations about inherited genetic predisposition should be left till a patient's cancer is advanced and incurable. The inherent vulnerability of the dying (Dean & McClement 2002, Karim 2005), alongside the sensitivity of the topic of inherited disease (Hallowell et al 2003), suggests that leaving discussion about familial risk should ideally occur before people require palliative care and would be better seen as an integral part of supportive care. Supportive care helps patients cope with their condition throughout their cancer journey (NCPC 2007). The way that Diane was able to draw on earlier reassurance from genetic specialists shows that support earlier in the cancer journey can continue to reassure patients as their condition deteriorates (p159).

Nevertheless, even within this model of care, suggesting that discussions about genetic predisposition are more appropriately seen as a role for supportive care services does not negate the fact that it may still remain an important issue within palliative care. This is because the family history may not have been taken in full earlier in the cancer journey and/or the fact that patients may not have had an earlier opportunity to discuss these concerns (Kirk 2004a). This can prevent other family members learning about their own risk of disease (and accessing health promoting measures) till the next family member is diagnosed with cancer (Kirk 2004a).

It has been suggested that disease progression, especially being told cancer is incurable, can provoke new fears about genetic disease (Rees et al 2001, Kirk 2004a). This is important because, if this is a common occurrence, it increases the requirement

to respond to these new fears. The findings from this study indicate that concerns are present in the dying but does not demonstrate whether these concerns were evoked by the dying process as suggested by Kirk (2004a) and Rees et al (2001), or whether they were unmet needs that predated referral to palliative care. Although the research literature that considers the effect of knowledge of genetic predisposition on people with cancer is limited (Hallowell et al 2004), it does, on balance, suggest that for many people concerns are provoked by diagnosis rather than progression to terminal disease.

There is, nonetheless, one paper that shows that concerns about inherited disease can be provoked by impending death from cancer. Hallowell (1999) interviewed forty-six women about their motivation for attending a genetic service for testing for genetic predisposition to breast cancer. All new clients who went to a regional clinical genetics service for an initial consultation over a year (1994-1995) were invited to participate (although women with a cancer diagnosis were excluded). She states that their attendance was strongly influenced by their sense of obligation to other family members. This included an obligation to the dead, and the study draws attention to nine participants who had been alerted to the possibility of genetic predisposition by a dying relative. These relatives had suggested that they seek advice about how to protect themselves. Hallowell (1999) shows that in some families the possibility of an inherited predisposition to cancer is discussed during the dying process and that these discussions have influenced the behaviour of surviving relatives. It is, however, noteworthy that even within the article she goes on to say that more women described their risk management decisions as being influenced by their obligations to living relatives than to dead (Hallowell 1999: 110). Although Hallowell et al has since written widely about the experience of predictive genetic testing, she has never again discussed the concept of an obligation to the dead, or the role of dying or deceased family members, as a

major motivating force (Hallowell et al 2002, 2003, 2004, 2005a, 2005b, 2006); rather these papers emphasise the obligation to other living family members, especially children.

There is also evidence that many people are aware of the potential for heritable cancer earlier in their cancer journey. For instance, Espen et al (2007) report the baseline data from a cohort study of 314 Canadians with colorectal cancer and a family history of colorectal cancer, who were undergoing genetic testing for HNPCC. Only two percent had advanced (Stage 4) disease. Over eighty percent of participants stated that their motivation for testing included wanting to know if their children were at increased risk of developing cancer in the future: the most commonly given reason for undergoing testing. This shows that concerns are present in many people with cancer prior to the knowledge that their cancer is incurable.

Wold et al (2005) carried out a survey of people with cancer to look at their knowledge of cancer causation. Over seventy-five percent of respondents were aware that cancer could be genetic. This level of awareness was not affected by whether respondents had a family history of disease. The survey had a check box design that asked about nineteen possible causes of three different cancers. There was no option for multifactorial causation; hence the survey may have encouraged the idea of monocausal causation. The survey did not provide insight into how people evaluated their own risk of susceptibility or understood the term genetic, nor did it ascertain whether they had acted on any concerns about heritable disease. Nevertheless, like Espen et al 2007, it shows a general acceptance that genetics played an important role in cancer causation, albeit in people with cancer who live in North America (Wold et al 2005), suggesting that it may frequently be possible (and indeed preferable) to discuss the topic of inherited genetic predisposition to cancer before patients require palliative care.



Hence 'outwith the genetics paradigm' it could be argued that it is acceptable for concerns about inherited genetic predisposition to primarily remain a missing discourse within palliative care. It could be suggested that the present model of care supports patients with the psychosocial outcomes of the disease within the family, albeit using different discourses to meet their individual needs. Specific concerns about inherited predisposition to cancer can be regarded as an 'anomaly' (Kuhn 1996), an aspect of care that in some way distorts the care needs of the dying, which would be better dealt with at an earlier stage in the dying process or referred to specialists in a different aspect of care.

It has, however, been argued by Lalloo et al (2000) and Kirk (2004a) that this response is inadequate. This study suggests it underestimates the challenge of caring for patients with a family history of cancer appropriately. For instance, it ignores the link between an inherited predisposition to disease and the likelihood of multiple bereavement, of developing cancer (and dying) at a younger age than normal, as well as the experience of multiple primary cancers and concurrent cancers in the family. It can also restrict the health promoting options available to other family members (Lalloo et al, Kirk 2004a). This study questions whether the present model of care '*achieves the best quality of life for patients and their families*' (NICE 2004, NCPC 2007) in these circumstances? It has been suggested that caring appropriately for patients with a family history of cancer demands a paradigmatic change in the theory and practice of nursing care (Anderson et al 2000). There has, however, been little discussion of what this means for palliative care patients. This is discussed below.

## **Within the Genetic Lens: A New Paradigm for Palliative Care?**

This section uses the findings from the study in conjunction with the research literature to show how giving care through a genetic lens would affect the physical, social and emotional dimensions of palliative care.

### Physical

It is proposed that the core difference with familial cancers is that, like all inherited genetic diseases, they are, by definition, family diseases (Richards 1996). Hence it becomes inappropriate to consider a patient's cancer in isolation from the family history of cancer: rather the patient's experience needs to be seen as an integral part of a familial experience. Here the concept that 'the patient is the family' (Richards 1996) and that the family is the focus of care (Peterson 2005) has to be central to all aspects of care. Consequently, assessment of the patient and their family's physical needs should be integrated and include a systematic assessment of the family history of cancer and, if appropriate, discussion of the health promoting measures that were available to relatives who were at increased risk of developing cancer in the future. This is fully in accordance with the World Health Organisation's definition of palliative care, which states that palliative care works '*through the prevention of suffering by means of early identification and treatment of...physical problems*' (WHO 2002).

This model of care would recognise that the death of a family member where the family history of cancer has not been taken into account may reduce the information and health promoting options available for other family members who are at risk of future disease. It would be recognised that leaving discussion about risk of an inherited genetic susceptibility until after a death has significantly more implications for families than not having discussions about lifestyle factors (like smoking, diet and exercise),

where epidemiological and population data is used to inform any discussion of risk. Failure to highlight genetic disease would have ongoing and lasting consequences for all palliative services. For instance, it would be difficult to imagine offering bereavement support to relatives without having actively ensured that every measure had been taken to reduce their risk of developing the same or a related disease.

Within this model information about genetic predisposition would be available for all patients with concerns about familial disease, irrespective of whether these concerns had previously been raised earlier in the cancer journey. Care for patients and families who had already been told their disease was associated with a genetic predisposition (like Harry p159), would aim to support them deal with this sequelae of this knowledge during the dying process. This may help families cope after death as Rees et al (2001) argue (from theory) that the family experience around the time of death may have a significant impact on the way people live with their potential for future disease afterward. Patients and families (like Diane p160) who remain concerned about familial disease despite being told that their family history did not indicate a genetic predisposition would be offered ongoing reassurance and explanation about the reasoning behind the conclusion. Patients who had not been able to discuss their family history of cancer previously (like Iain p161) would be provided with a supportive environment where the topic could be raised and discussed. This would include the documentation of the family tree, as well as support for any psychosocial concerns that arose from previous experiences of cancer. If the family history of cancer met the guidelines for referral to a specialist, (see appendix one), a rapid referral process would be expedited.

Consequently, it will be important to be aware of the effect that knowing about an inherited predisposition has on people with cancer. There are two studies that consider

how the knowledge of a genetic predisposition (that has been confirmed through genetic testing) affects people with cancer. These both report complex interactions between the knowledge of heritable disease and concern about their own and other family members' future.

Hallowell et al's (2004) retrospective qualitative study considers the effect of genetic testing on thirty women with breast cancer. It concludes that for many participants genetic testing was one of the most positive things to emerge from the cancer experience, as it allowed them to act altruistically to enable other family members to make informed decisions about their future health (Hallowell et al 2004: 263). They state that for the majority of women the risk of cancer recurrences had become an integral part of their self-identity prior to testing, and only a small group of women felt threatened by positive test results and the associated uncertainty about their future health (Hallowell et al 2004).

Bonadona et al (2002) interviewed twenty-three participants with cancer who had tested positive for a genetic predisposition to cancer. All eligible clients who had attended one French clinic were invited to participate. (Twenty-three percent of the potential participants had died before the study commenced). Bonadona et al document how participants had increased concerns about their own future deaths following testing and had an increased awareness of the risk of cancer reoccurrence. Quotes like '*I'm not cured: that means relapse, death and horror*' (Bonadona et al 2002: 100) are used to emphasise the emotional impact of a positive test result. Despite these concerns, none of the participants regretted testing as it allowed them to plan for the future and enabled them and their children to access regular screening for (re)occurrence of the disease. Bonadona et al (2002) suggest that it was the knowledge of inherited disease (through testing) that strengthened the fears for self and relatives as opposed to the pre-existing

diagnosis of cancer. Nevertheless, both Bonadona et al (2002) and Hallowell (2004) found that participants had no overall regrets about testing because it had led to increased surveillance for them and their families.

These studies complement this study which looked at the people with advanced terminal disease, where fears about recurrence were redundant, but perhaps were replaced by an increased awareness of the dying process due to the family history of cancer. Unlike this study they describe the experience of people who were actively engaging with specialist genetic services. However, the fact that Bonadona et al (2002) and Hallowell et al (2004) found that even people who had been informed that there was an inherited predisposition within the family were helped by this knowledge (because it enabled relatives to make informed decisions about their future health), shows how open discussion of concern can be beneficial to patients and families.

### Social

The findings draw attention to the diverse ways that the family history of cancer could affect the social dimensions of care. They show how multiple deaths within the family, dying at a younger age than normal, and the experience of concurrent cancers all had the potential to affect the social needs at death. However, despite their different family circumstances the patient-participants consistently emphasised how this had affected their family cohesion and communication patterns. This suggests that the effect on family cohesion and communication of previous experiences of cancer within families will become increasingly important when caring for patients within the genetics lens. It emphasises the need to question whether poor family cohesion and communication patterns may be due to a genetic predisposition, and whether this may prevent relatives from accessing health promoting measures.

Family communication about disease is an important issue for health services that support people with genetic predisposition to disease as it is the primary way that people learn about their own disease risk (Forrest et al 2003). Hence there are several studies that examine this issue. Although no study was found that directly focused on the effect of death on family communication, it is relevant to this study that several reported the way that certain deaths within participants' families had affected family communication. For instance, Kenen et al (2004) identify five different family communication styles. They show that previous deaths in the family can block or partially block communication, saying that in some families 'the script is to agree not to talk about the loss of a sibling or a mother' (Kenen et al 2004: 340). Total blocking of communication meant that some relatives had totally refused to discuss particular familial deaths. Indirect blocking occurred when family members who did not want to discuss familial cancer made subtle signals about this rather than overtly cutting off conversations. Hiding past family illness also indirectly blocked family communication: one participant only had learnt that two aunts had died at a young age from breast cancer after she herself had developed the disease. In this study, the deaths of parents with dependant children appeared to be the biggest block to knowledge about family disease, primarily because of the difficulties that the dying parents had discussing their illness with young children, but also because of the way family structures changed following the parent's death.

Foster et al (2004) looked at some of the dilemmas women faced when talking about inherited breast disease within families. They show that women anticipated taking a key role in encouraging adult nieces and nephews to be tested following the death of a sibling, whilst trying to respect their in-laws' ways of coping with familial cancer. Nonetheless, death had altered the family structure and thus the flow of

information between relatives. Foster et al (2004) also highlight that many participants felt isolated following disclosure of positive test results as the people they most needed to support them (mostly mothers but also sisters) had predeceased them. The study only included women who had attended a specialist genetics clinic for predictive genetic testing for BRCA 1/2; nevertheless their findings echo the findings of this study of men and woman receiving care from a hospice. The effect of previous deaths appeared to be more extreme in this study - with two participants (one male and one female) taking on a more overtly parental role through adoption/legal guardianship following a death, whilst others felt discouraged from maintaining contact with nieces and nephews because of difficulties in maintaining the relationship with in-laws.

Forrest-Keenan et al (2005) looked at the barriers and facilitators to family communication about genetic risk. Death is never explicitly highlighted as a barrier but is discussed in several of the themes that emerge. It is reported as influencing the decisions about whose responsibility it was, (or was not), to tell relatives about genetic predisposition to disease. Although they report general agreement that it was primarily a parental role (even with adult children), there was evidence of family discord about whose responsibility it was to inform the adult children of deceased siblings, especially if the surviving parent was reluctant to raise the issue.

Hence these studies acknowledge that death can affect the way families communicate about genetic disease; nevertheless death is not their main focus. Only Kenan et al (2004) discuss the nature of the deaths that had affected their participants' ability to communicate. They state that communication and the family script '*was traumatised by the death of a relatively young family member, particularly when children were left motherless*' (Kenan et al 2004: 343). The death of either parent was

shown to profoundly effect family communication and cohesion in this study, and this in turn continued to affect the dying process of patient-participants.

Hence, both the findings from this study and the literature suggest that within the genetics paradigm caring for patients with a family history of cancer would involve facilitating family cohesion to support family members who need to communicate about cancer, especially when death occurs at a young age. This accentuates the need to ensure that the family history is documented prior to death and discussed with all appropriate family members. It may also involve helping patients with young children consider who might be the appropriate person to discuss genetic predisposition to disease following parental death.

This also underlines the need for nurses to consider why family cohesion and communication may be poor. If this is due to a family history of cancer it becomes important to assess the risk of genetic predisposition and help ensure that all family members are informed of this if appropriate. Two participants within this study (Claire and Iain: see p153) were actively trying to restore links with first degree blood relatives in order to re-establish emotional and social bonds with them. However, within the genetic lens the need to re-establish links with other family members will also be driven by a concern to share information about the family history of cancer (Finkler 2000).

### Emotional

The fact that concerns about familial disease are likely to occur in scenarios that both patient and nurse-participants described as inherently stressful, (including the deaths of adults with dependant children, concurrent cancers within the family and the potential for overwhelming distress due to previous familial deaths), underlines that concerns about genetic predisposition will be present in scenarios where there are



already complex emotional needs. Although, (as discussed above p241), Bonadona et al (2002) and Hallowell et al (2004) show that knowledge of genetic predisposition need not be distressing for people with cancer, there is evidence that this knowledge can be associated with guilt, distress and isolation in relatives (Hallowell et al 2006, Keenan et al 2006, Van Oostrom 2007: discussed p35). Hence a wide range of emotional response should be anticipated in patients. This suggests that communication about familial disease has the potential to add complexity to scenarios that are already complex emotionally. However, many of the skills required to provide emotional support to terminally ill patients may be transferable to this new scenario. As noted above, the communication skills proposed for generic nurses discussing genetic issues are based on guidelines developed to help promote appropriate discussion about death and dying (Daly et al 2001).

It must also be noted that palliative care services regularly care for patients and families who have experienced the deaths of individuals who die at a younger age than normal, multiple bereavements, and concurrent cancers. Care within the genetic lens offers a new hope to families in these situations as tailored health promoting measures may prevent these scenarios from re-occurring in future generations. Conversely, care outwith the genetics lens denies this hope to patients and reduces families' future options for health. Hence it is suggested that giving care within the genetics paradigm will alter the physical, social and emotional dimensions of care for patients with a family history of cancer.

On reflection, however, there is one significant limitation to this model of care. The focus on 'the patient as the family' (Richards 1996) could be interpreted as meaning that patients and family members have the same needs. This is patently not the case when one family member has advancing, incurable disease. The needs of the dying are

different to those who are at an earlier stage in their cancer journey, or relatives who are potentially anticipating future disease. Whether the genetics model suggested here, which is primarily based on research with patients at an earlier stage in the cancer journey (Hallowell et al 2004, Bonadona et al 2002), or with concerned relatives (Kenan et al 2004, Foster et al 2004, Forrest-Keenan et al 2005) is appropriate for dying patients has yet to be explored. However, the widespread concerns about familial disease found in this study shows that a model of care that appropriately deals with patients' and family's concerns about future disease, which can be delivered as an integral part of the care of people with advancing terminal disease needs to be developed.

### **Summary of Different Paradigms**

Two different models of care for patients with a family history of cancer are presented above. The first model, 'outwith the genetics paradigm' reflects the care described by the participants in this study. Although care of the family is integral to care (Twycross 2003, NCPC 2007), only the physical needs of the person with advanced terminal disease are considered. As documented (p219) the patient-participants consistently and spontaneously praised the care at the participating hospice. Nonetheless, findings from this study showed that the patient-participants had concerns about their family history, which were not being fully addressed within the present discourse. These concerns were considered from a particular interpretive stance, from 'within a genetic lens,' and a new model of care proposed. The different assumptions that underpin the models of care are summarised in Table Nine (below).

**Table 9: The difference between the two paradigms**

	<b>Outwith the Genetic Paradigm</b>	<b>Within the Genetic Paradigm</b>
Definition of Cancer	Disease in which abnormal cells proliferate in an uncontrolled fashion and spread throughout the body	A multifactorial disease of the human genome
Definition of Family	Carer: Strong emotional and societal bonds	Blood-kin
Focus of Nursing Care	Patient and carers	The Family is the Patient
Significance of Aetiology	Peripheral	Important: Other family members may be predisposed to cancer

Outwith the genetics paradigm care is focused on individuals with cancer (Saunders 2001). Cancer is culturally defined as a disease in which the abnormal cells proliferate in an uncontrolled fashion and spread throughout the body (Kleinsmith 2006). As palliative care does not focus on cure the aetiology of cancer has little significance. It does not affect the assessment of patients' physical care needs. The aim of social and emotional care is to support individual patients and people with strong emotional bonds to the patient. Little attention is paid to why certain families have particular social support structures or distribution of cancers within the family. The family history of cancer has a minimal impact on the care needs of patients. The aim is to support patients so that they can cope with any emotional distress due to previous occurrences of cancer, rather than to evaluate the reasons for the previous deaths within the family and their implications for the future.

Within the genetics paradigm cancer would be defined as a multifactorial disease of the human genome. The aetiology of disease would be important because it can indicate that other family members are at risk of developing cancer in the future (Bell

2004). Hence the physical implications of disease for all family members would be integrated into care and an assessment of cancer within the family (not just the individual) would be integral to care. This is to expedite the early identification and treatment of other family members at risk of a genetic predisposition to cancer, as this associated with improved mortality and morbidity outcomes (Richards 1996). The emotional care of patients would encompass concerns about other family members developing cancer. Social dimensions of care would encompass an assessment of family communication and cohesion as this is essential to minimising the potential for future disease in other family members. The indications of an inherited genetic predisposition to cancer would be widely recognised (see Table Two p17), and particular attention given to supporting families to help them communicate about familial disease in these circumstances. As up to one in ten cancers are thought to be associated with an inherited predisposition to cancer (Claus et al 1991) expertise in familial cancers would be integrated into the multidisciplinary care team.

Which model of care will be perceived as appropriate in the future depends on many factors. However, it has frequently been noted that although the transition from genomic research to clinical genetics in multifactorial disease like cancer may take time, it appears to be inevitable (Bell 2004, Kirk 2004b). Since this study started there have been many diverse changes that may promote an increased awareness of the importance of genetics predisposition. This includes (but is not restricted to) the legalisation of embryo selection for a genetic predisposition to breast and bowel cancers ([news.bbc.co.uk](http://news.bbc.co.uk) 08/05/2006), the identification of a new mechanism for transgenerational inheritance (Hitchens et al 2007), and the proposal that the protocols for cancer screening should not be based on age as a proxy for risk but offered to everyone with an increased risk whether this is due to age and/or a family history of

disease (Pharoah 2008). Findings from this study show that patients already have concerns about familial disease, hence it is suggested that the family history of cancer cannot long remain a missing discourse and that palliative services need to be equipped to give appropriate care to people with concerns about this issue.

However, although the findings from this study highlight the need for a change in the model of care for patients who have a family history of cancer, they also draw attention to two barriers that may hinder this change. These are described below.

### **Barriers to Paradigm Change**

Changing paradigm is difficult because the decision to accept a new worldview is always a decision to reject a previously held perspective. Kuhn (1996) states that it frequently takes a generation for a new worldview to become accepted because many individuals find it hard to reject their understanding of a phenomenon and to discard their old methods of working. Changing paradigm means that previously held assumptions, like how to provide optimum care to patients and families, must be questioned. It challenges people not only to review their traditional ways of responding to a phenomenon but also to learn new skills as they get to grips with the implications of the new information (Kuhn 1996). However, despite this, paradigm change occurs because it leads to solutions to problems that are insoluble using the old discourse (Kuhn 1996).

It is important to note that caring through a genetic lens should not ultimately increase workload as the traditional paradigm already integrates the care of the family. Rather it will alter the way that patients and families with a family history of cancer are cared for, ensuring that reassurance is given to people with unnecessary concerns and action is taken where there is the potential for an inherited genetic predisposition.

However, changing paradigm would have implications for both patient and nurse education. This is because findings suggest that there are two significant barriers to paradigm change which would best be overcome through education. These are a) the poor understanding of cancer as a multifactorial disease and b) the novice practice of nurses.

#### a) The Poor Understanding of Cancer

The patient-participants had a limited understanding of the aetiology of cancer. This was juxtaposed with scepticism about the many given causes of cancer. As discussed in Chapter Nine, health behaviours are influenced by the understanding of disease (Ajken and Fishbein 2005). Hence these factors may be a barrier that prevents patients from acting on concerns about familial disease. None of the participants had a concept of multifactorial cancer causation. This is significant because individuals need a clear coherent account of how risk factors are linked to disease to motivate behavioural change (Rees et al 2007). Hence the idea that cancer occurs due to a series of steps that are triggered by different causal factors (Nowell 1976, Kleinsmith 2006) might help reduce patient scepticism about the different risk factors for cancer and increase the understanding of the links between an inherited predisposition to disease and lifestyle and environmental factors.

The poor understanding of multifactorial disease was accompanied by a very basic knowledge of genetics and/or cancer. Several participants were unclear about the details of their own disease. Three were unclear about the nature of their own primary cancer and others appeared to believe that all cancer was the same. Similarly, half of the participants were unclear about the cause of death of (at least) one first-degree relative.

Unfortunately this lack of knowledge about cancer, genetics and inherited susceptibility could be a barrier to patients acting on their concerns about familial disease. Nevertheless there was some evidence to suggest that knowledge of genetic predisposition may cause people to re-evaluate their past experiences (p162). Hence people who view their illness through a genetic lens may come to evaluate the cancer within their family differently as different aspects of the phenomenon take on different meanings within the new paradigm. For instance, the significance of multiple primary cancers and the fact that individuals within a family develop cancer at a younger age than usual may become more pertinent for patients in the future.

The poor understanding of cancer found in this study is reflected in the research literature, suggesting that it be a significant barrier when discussing the implications of familial disease. Wold et al's (2005) survey of the knowledge of cancer causation in people with cancer (discussed above), found that their beliefs differed substantially from those of experts. They overestimated the importance of stress and environmental causes and underestimated lifestyle causes (Wold et al 2005).

Much of the literature that looks at the understanding of an inherited predisposition to cancer within the United Kingdom has focused on the understanding of the aetiology of disease in first degree blood relatives of people with adult onset multifactorial disease, including cancer, heart disease and diabetes mellitus. Walter et al (2004) review and synthesis of this literature emphasises the commonalities between the different diseases. They discuss how a healthy relative's assessment of risk is not primarily based on a systematic evaluation of their family history but on the salience that this history had for individuals, including the degree of emotional closeness to affected relatives. Individuals' personal models of disease were often found to differ from the medical model. Walter et al (2004) highlight that different constructions of

disease can make communication between health care professionals and families difficult. This review of the literature suggests that the poor understanding of multifactorial disease found in this study is widespread within Britain.

However one study, undertaken in Sweden by Arman et al (2006), does report a good understanding of the multifactorial nature of breast cancer. This study used qualitative interviews to analyse the differences between breast cancer patients opting for treatment in an anthroposophical hospital compared to a general hospital. They found similar beliefs and perceptions about the aetiology of disease amidst the two groups. It was found that 'the majority of participants felt that different factors in life had influenced the genesis and course of their cancer' (Arman et al 2006: 144). Although patients mentioned external factors like diet, tobacco, alcohol, endocrine drugs, environmental triggers and stress, they were considered in combination with genetic factors, which were thought to combine to produce disease. They note that some participants who had a family history of breast cancer were convinced that their own cancer was purely hereditary, and that these participants therefore felt that their lifestyle choices had not influenced the development of their disease. Although Armand et al do highlight scepticism about the aetiology of cancer, they say it was only mentioned by a fifth of the participants whilst it was the overwhelmingly dominant theme in this study. The lack of scepticism reported, might be related to the more sophisticated understanding of the disease process or the fact that all the women interviewed were still having active treatment for disease or in remission following treatment. As the participants lived in Sweden they will also have had access to different information about the aetiology of disease. Nevertheless Armand et al (2006) show it is possible for patients to be informed about multifactorial disease.



In contrast, the research literature discussed above suggests that the limited understanding of the aetiology of cancer found in this study may be widespread within the United Kingdom. This could be a major barrier to the implementation of a model of care based on a genetic paradigm. It could even be argued that people who do not recognise a need do not have one! However, there are ethical and legal consequences for healthcare professionals who ignore a predisposition to cancer and its potential to affect other family members (Morgan 1996, Hope 2004). At the very least it could lead to a breakdown in trust when the next member of the family develops cancer and learns that they had not been given information that would have facilitated access to appropriate health promoting services. In addition, nurses are expected to uphold the rights of all clients to informed decision making and voluntary action about the risk of familial disease (Kirk et al 2003, Haydon 2005). It is surely more appropriate to take the challenge of health education seriously and to research ways of promoting a better understanding of multifactorial disease, with the aim of breaking down the barrier that a poor understanding of the aetiology of cancer presents to the appropriate care of patients with a family history of cancer.

#### b) Novice Practice

The second barrier to changing to a genetics paradigm for patients with a family history of cancer was that the nurse-participants were novice (Benner 1984: see p219) at providing care within the genetics lens. They clearly stated that they did not feel that they had the appropriate knowledge or clinical expertise to provide suitable care for patients with a family history of cancer. They described complex scenarios where they were aware of the potential for a genetic predisposition to cancer but highlighted the difficulty they had in prioritising and openly discussing these concerns. This occurred

despite the emphasis placed on caring for families within palliative care outwith the genetics paradigm.

There is some research that suggests that the nurse-participants were not atypical in their inexperience in this aspect of care. As discussed (p28), Clifford et al 2007 surveyed hospice nurses to learn about capacity and training needs in supporting end of life patients with genetic conditions. This survey suggests that there is a widespread lack of confidence in caring for patients with a genetic predisposition to cancer. It found that seventy-six percent of adult nurses from forty adult hospices rated themselves as 'not at all confident' at integrating genetics into clinical practice (Clifford et al 2007). Respondents consistently rated themselves as having low confidence levels in the clinical, biological and psychosocial requirements of care, despite fifty percent of participants indicating that they felt it was an important issue for palliative care. Ninety percent of respondents had never referred a patient to genetic services although eighty percent indicated that they would be interested in receiving further training in this aspect of care. However, the survey, like this study, was restricted to qualified nurses and did not consider the role of other members of the multidisciplinary team in caring for families with a family history of cancer. The response rate was low (29%). It is not known why many nurses choose not to respond but it might be because they did not see the relevance of genetics (Clifford et al 2007). Nevertheless it is a large survey (N=328). It suggests that the views of the nurses in this study who felt that they had an inadequate knowledge base to appropriately support families who were concerned about genetic predisposition reflect concerns that are common to other palliative care nurses.

Nurses are expected to demonstrate a knowledge and understanding of the role of genetics and other factors in maintaining health, to underpin effective practice (Table

One p16, Kirk et al 2003). This highlights the need for more education about inherited susceptibility to disease for nurses working in palliative care. However, learning within a new paradigm does not only mean learning new skills but learning to see the world anew (Kuhn 1996). Hence more information about genetic predisposition to cancer may not be enough to change practice; rather role modelling from expert practitioners who can demonstrate expert care may be needed to show how care can be given within the genetic lens. It is important to develop these skills as novice practice has the potential to do harm both, through provoking unnecessary anxiety and ignoring patient fears. It may even allow patients to die without having had the opportunity to assist relatives through documenting the family history of cancer, undergoing genetic testing or banking blood to facilitate testing in the future. Competent practice (Benner 1984) will help ensure that families with an inherited genetic predisposition receive the optimum support available, promote understanding of the multifactorial nature of cancer and provide reassurance to patients with a family history of cancer that the cancer within their family is being appropriately managed.

### **Implications for Practice**

All healthcare professionals are expected to be confident and effective when dealing with multifactorial disease (DH 2003). This study has explored the meaning of a family history of cancer for palliative care patients. As discussed above, a key implication for practice is to develop a model of care that provides ‘the best quality of life for patients and their families’ with a family history of cancer (NICE 2004, NCPC 2007). Findings have described how the physical, social, emotional and cultural dimensions of care are subtly modified when viewed through the genetic lens. Table

Ten summarises the key differences between the two models of care presented in this study.

**Table 10: A Comparison of Care Needs between Paradigms**

<b>Dimension of Care</b>	<b>Outwith the Genetic Paradigm</b>	<b>Within the Genetic Paradigm</b>
Cultural	Aetiology of cancer unimportant	Aetiology of cancer is important as knowledge of an inherited genetic predisposition alongside tailored health promoting measures can reduce morbidity and mortality in relatives
Physical	Focus on the individual experience of cancer: e.g. symptom control	Consideration of whether the distribution of cancer within the family indicates an inherited genetic predisposition
Social	Focus on supporting caregivers and people with strong emotional bonds to the patient	<p>Consideration of whether (and how) the family history of cancer has affected family cohesion and communication with particular regard to deaths from cancer that occurred at a younger age than normal</p> <p>Reflection on the way the family history affects the family's ability to provide social support to the patient and consideration of how this affects the family's ability to communicate about cancer</p>
Emotional	<p>Focus on care of patient (and family) as patient lives with the reality of advancing incurable disease and forthcoming death.</p> <p>This includes supporting patients who have a range of emotional needs due to the effect of previous deaths in the family</p>	Supporting patients and families who know their family history is associated with an inherited predisposition and families who are concerned that this is a possible reason for the cancer in their family

It is suggested that there are four priorities for service development to ensure that the care needs of patients with a family history are provided in an appropriate manner.

- A. The most urgent implication for practice is to ensure that all nurses have the ability to uphold the right of all patients to informed decision making and voluntary action. This is a core competency for all nurses (Table One p16). Even the suggestion that concerns might be more appropriately dealt with earlier in the disease trajectory does not negate the fact that palliative services will often be the last opportunity for patients to make an informed decision about whether to act on concerns about inherited genetic predisposition.

This means that nurses have to learn to listen to, and act on, the concerns of patients who are concerned about other family members developing cancer in the future. The widespread nature of the fears expressed by participants suggests that the care of patients with these concerns might best be designed with two separate objectives in mind. Firstly, it highlights a need to reassure people with a family history of cancer that did does not automatically indicate an inherited genetic predisposition. This would be aimed at preventing people from dying with unnecessary fears about their family's future health. Secondly, it underlines the need for palliative services to develop appropriate strategies for patients whose concerns are appropriate.

- B. Nurses are expected to obtain and communicate credible, current information about genetics to patients (Table One p16, Skirton and Barnes 2005). However, the novice level of the nurses underlines the need to develop education and training programmes that allows them to develop their clinical expertise and knowledge base, and equips them to provide competent care that encompasses the core genetic competencies.

- C. Nurses are also expected to appreciate the importance of sensitivity when communicating information about genetics and to provide this information in an appropriately tailored manner (Table One p16, Middleton et al 2005). This accentuates the need to develop the appropriate communication skills to facilitate discussions with patients who are concerned about their family history of disease. Discussing inherited genetic predisposition with patients who have advanced incurable disease may present complex challenges for palliative services as they attempt to convey complex ideas about disease aetiology and health promotion to concerned patients and families during an inherently stressful family time.
- D. Nurses are expected to recognise the limitations of their own genetic knowledge (See Table One p16, Benjamin and Gammet 2005). This emphasises the need to develop links with specialist genetics services to ensure that patients and their families, who have a family history of cancer that indicated the potential for an inherited genetic predisposition receive expert care, including advice about how to access appropriate cancer prevention measures. The appropriate expertise to support families with concerns about familial cancer also needs to be integrated into the multidisciplinary care team.

### **Priorities for Further Research**

As noted, there is a very limited research literature about the effect of knowledge of inherited genetic predisposition to cancer on people with cancer. Hence further research into almost any aspect of this study, especially if the research focused on people who have not attended specialist genetic services, would add to the knowledge

base. However, the priorities for research highlighted below indicate issues that might be especially pertinent in ensuring that the care needs of palliative care patients with a family history of cancer are appropriately met.

1. No relatives were recruited into this study. Further research is needed to more fully understand how to support relatives who fear that they may go on to develop the same disease in the future. It is a priority to assess whether they too have concerns that are not presently being addressed by palliative services.

More research that considers the needs of palliative care patients would also be useful to ensure that patients receive appropriate care. This would include:

2. Case studies that demonstrate the provision of expert practice in the delivery of care to palliative patients with concerns about an inherited predisposition to cancer. This would help disseminate knowledge of good practice.
3. A longitudinal study of cancer patients' experience would help untangle whether the concerns about inherited genetic susceptibility were associated with advancing disease, or were frequently present earlier in the disease process. This would help ascertain whether it would be more appropriate to target resources into supportive or palliative care services.

Further research into how to overcome the two major barriers that restrict the care of palliative care patients with a family history is also important. That is:

4. Research into how best to provide appropriate education for palliative nurses that will help them develop into competent practitioners when caring for patients with a family history of cancer.

5. A study that considers how best to communicate the multifactorial nature of cancer to patients would be helpful in enabling nurses to develop this skill.

## **Conclusion**

This study is important because it identifies how the meaning of a family history of cancer is being altered by the knowledge that familial cancer can be associated with an inherited genetic predisposition. It proposes that the care needs of palliative care patients with a family history of cancer are changing in response to this. It suggests that the traditional paradigm, where the care needs of patients with a family history of cancer is a missing discourse, is no longer appropriate. The findings from this study are used in conjunction with the literature to propose a new model of care for patients with a family history of cancer. However prior to acting on research it is important to evaluate the research methods and methodology and their appropriateness to the research question (Greenhalgh 2006). This is the focus of the next chapter.



## CHAPTER ELEVEN: STRENGTHS AND LIMITATIONS

*If we knew what we were doing it wouldn't be called research, would it?*  
(Albert Einstein 1879-1955)

### Introduction

This chapter presents the processes used during the research to ensure that the methods used were credible and trustworthy. The strengths and limitations inherent in the research methodology are discussed first, and then the strengths and limitations of the research methods are considered. Other minor limitations and strengths indubitably exist but it is hoped that enough methodological data has been included in Chapters Three and Four, which document the research process, to allow them to be evaluated in context.

### Methodology

The aim of phenomenology is to learn about a phenomenon not to prove a theory about it (Flyvberg 2006). The central strength of a phenomenological approach for this study was that it provides methodological and philosophical support in the attempt to capture and express the meaning of a significant human experience in a rigorous manner (Todres and Holloway 2006). Hence the research has strived to represent and conceptualise the experience of a family history of cancer.

Phenomenology does not give any indication of the distribution or frequency with which the phenomenon occurs. This is frequently referred to as a lack of generalizability and is sometimes described as a shortcoming of the chosen methodology (Mason 2002, Silverman 2005). However generalizability in qualitative study is obtained through the development of meaning (Morse 2007), and if the concepts are well described they should be recognisable and resonate in other places (Morse 2007). Consequently, if the given description accurately represents the features

of the phenomenon it will have resonance with others interacting with the phenomenon (Pyett 2003). This occurs when evidence is grounded in concrete, context-dependant, real-life experience (Flyvberg 2006). This resonance occurred during the research process (see real world validity below).

This study did not aim to measure or quantify the effect of a family history of cancer but to provide a deeper knowledge of the meaning and lived experience (Morse 2007) of a family history for palliative care patients. It was undertaken because it was thought to be important to learn more about the phenomenon of a family history of cancer within palliative care, and because, as Flyvbjerg (2006) states, the power of an in-depth examination and intense observation is often underestimated in social research.

Qualitative research has been foundational to the social sciences disciplines (Morse 2008) and the practice of palliative care. For instance, Glaser and Strauss (1965) *Awareness of Dying* helped promote the benefits of open communication about death to the benefit of palliative patients (Searle et al 1997). *On Death and Dying* (Kubler-Ross 1969) had a profound impact on the way the dying process is considered. It helped prepared the ground for the growth of the hospice movement in North America (Saunders 2005). Like all research, the findings and methodologies of these seminal studies have been extensively questioned but they do demonstrate that palliative care is embedded in knowledge that is derived from qualitative research, despite the inherent methodological difficulties in generalising findings.

The fundamental strength of using the principles of a Heideggerian hermeneutical phenomenological methodology for this study was that it allowed an exploration of the sensitive topic of the family history of cancer with potentially vulnerable terminally ill patients. With this methodology researchers are expected to make their preconceptions explicit so that readers can evaluate the strengths and limitations of the interpretation

made (Todres and Holloway 2006). In this study the crucial explicit assumption made is that the understanding of the biological mechanisms that lead to an inherited susceptibility to cancer is an important and significant change that has the potential to affect health care needs. Hence the concept of 'the genetics lens' has been explicitly used as an interpretative framework (Todres and Holloway 2006) to draw attention to particular aspects of the participants' experience of cancer.

This is clearly illustrated in the relational analysis, which is based on the participants' account of how they had experienced previous occurrences of cancer within their family. Due to the active choice of the researcher these accounts were considered in a particular manner. This influenced the decision to focus the discussion around the effect on family communication and cohesion and how this affected the participants' ability to know about their family history of disease. This choice reflects the importance of family communication when caring for people with inherited susceptibility to disease (Foster et al 2004, Forrest-Keenan et al 2005). Information about these subjects was abundant in the interview transcripts, however the same data considered through a feminist or psychological lens could have produced a different analysis.

This ability to see and express something from a new perspective is a crucial dimension of phenomenology's discovery-orientated approach (Todres and Holloway 2006) but is also one of the core concerns about the generalizability of the findings (Mason 2002). The need to be alert to the multiple ways of seeing things (Carter and Little 2007), however, has not detracted from the desire to demonstrate a truth, if not the truth (Frank 2004), about the evolving care needs of patients. Nevertheless, reflexive attention to the perspectives that informed the research methods, as well as attention to the inherent strengths and limitations of the research methods, is required

when evaluating the strengths and weaknesses of hermeneutic phenomenology (Frank 2004, Cutcliffe 2003).

The use of Van Manen's (1990) interpretative framework was pivotal to the construction of the phenomenological analysis. His concept of lifeworld existentials provided a systematic way of reflecting on the nature of the phenomenon of a family history of cancer for palliative care patients. It provided a systematic way of considering what constituted the essence of the lived-body, lived-space, lived-relationship, lived-time and lived-knowledge for participants. It enabled systematic reflection about what data constituted part of the meaning of the family history of cancer for the participants. Nevertheless there are other ways of maintaining a strong and orientated approach to a phenomenon (for instance exegetically with other phenomenological descriptions), which would have given the analysis of the phenomenon a different orientation.

This research was undertaken with the awareness that the knowledge gained would be situated and contextual. This does not automatically nullify any relevance of the findings to other situations, rather that the findings have to be interpreted and translated with care due to the way that the findings arose both out of the context of the research process and the situated experience of the research participants.

## **Methods**

### The Interview Proforma

A phenomenological interview needs to be disciplined by the fundamental question that prompted the interview (Van Manen 1990). The interviews were guided by a semi-structured proforma (See Appendix Four & Five). In retrospect, the proforma was focused on a very narrow and potentially biased concept of the nature of a family

history of cancer. It primarily focused on the effect of previous occurrences of cancer within the family and how this affected their dying process. In practice, the patient-participants' responses consistently focused on how they, and their experience of living, had been affected by different experiences of cancer. They consistently emphasised two aspects of inherited susceptibility to disease that the researcher was intellectually aware of but had not thought to call attention to during the interviews: the affects of young deaths on their family life and living with multiple primary cancers. The richness of the interview data was preserved by the strategy of using open questions based on predetermined themes (Robson 2002). The use of a semi-structured interview format minimised the shortcomings inherent in the preconceived concept of a family history within the interview proforma.

The proforma also focused on the nursing needs of patients. Reflexive attention to the data, (perhaps best seen in Chapter Six), suggests that the participants did not primarily see themselves as palliative care patients, but as people. Living with a terminal illness was only a part of their self-identity. Hence the findings contain a tension between the participants' self-identity and the research focus on palliative care.

Biographical detail was not systematically collected about the research participants in this study. This was intended to make the interviews feel like a conversation with a purpose (Burgess 1984), and to encourage participants to speak freely about their experiences (Robson 2002). However as the analysis progressed age became an increasingly important factor and information about all the patient-participants ages would have enhanced the analysis.

Lastly, the interview proforma contained no prompts about the younger generation of the family. Questions about this topic were forbidden by LREC as they felt it increased the potential for the study to cause emotional distress to unacceptable levels.

It is a limitation of this study that it was not possible to probe about how participants communicated with their adult/children about inherited disease. The information about this is therefore much thinner than the information about how the participants' own childhoods were affected by familial cancer.

### Interviews

Both participants in an interview are actively involved in constructing meaning during the interview process (Holstein and Gubrium 2004) and the researcher can be considered as the main instrument of data collection (Sorrell and Redmond 1995). Consequently, it is important to consider reflexively the effect that the interviewer had on the interview process (Nunkoosing 2005, Hewitt 2007).

I am an experienced palliative care nurse who has received professional training in communication skills. These were used to try to ensure that the participants felt attended to and heard. I used body language, eye contact and verbal responses to achieve this. I deliberately took an empathetic stance when participants told of their experiences

Researcher (I1): *No wonder you feel alone, I'm sorry, just listening to you, it's heavy*

Researcher (I6): *No wonder you said it was frightening*

This sometimes meant attending to information that was not directly relevant to the research topic before returning to the research agenda. The extract below shows how one participant led the conversation into an area that he wanted to discuss.

Participant (Iain): *We haven't spoke about how me missus feels have we?*  
Researcher (I9): *No, no yet but I'll ask you. How does she feel?*

Although I made consistent efforts to be empathetic about the patient experience, this was balanced by a need to ensure that I did not ask leading questions or give leading

prompts about the nature of the lived-experience of a family history of cancer, as the whole purpose of the interviews was for the participants' experience of the phenomena to emerge. For this reason I was constantly guided by the interview proforma which was always physically present and referred to during the interview. This may have increased the formality and stilted the flow of participant information during the interviews.

Researcher (I1): *I'm jumping quite a lot of questions here, but because you're talking about feeling alone, I just want to ask if you are able to discuss any of these things with your family?*

Researcher (I2): *That leads on, quite clearly to my next question, which is...?*

It is important to note, however, that the participants were just not passive providers of data (Nunkoosing 2005), but had their own motivation for participating in the research. Several participants spontaneously gave diverse reasons for participating; the most common reason was a desire to help other patients in their situation. This was commensurate with the stated aims of the research, which was explicitly mentioned in the participant information sheet (see Appendix Seven)

It is hoped that information from this study will help hospices understand how best to support other patients and families in a similar situation to your own in the future (Patient Information Sheet)

Other reasons given included a desire for memorialisation with one participant expressing interest in where the research would be published

*Will it be in the Lancet or the BMJ or somewhere like that, that it will be published? (Anne)*

Other participants clearly wanted to do anything they could to protect other family members in the future (see theme 'No man is an island'), whilst some participants just seemed to want to be helpful. Lastly, one participant appeared to want to talk with me about my understanding of the aetiology of cancer. This was done, at length, at the end of the interview when the tape recorder had been switched off. The nurses most

commonly stated that it was an interesting research question and they wanted to support the research.

### Participant Characteristics

Commonly identified factors that can influence the outcome of interviews include age, gender, race, role, and locality (Manderson et al 2006, Hewitt 2007, Nunkoosing 2005). The researcher was a white, female, palliative care nurse, characteristics shared by all the nurse-participants. However the patient-participants' characteristics were more varied

- The fundamental difference between interviewee and interviewer in this study was that the researcher was undertaking a PhD both to enhance the understanding of patient care needs and enhance her future prospects, whilst the participants were identified as having an advanced incurable cancer. This meant that the interviewees were 'privileged' knowers' (Nunkoosing 2005) about the experience of terminal illness. Unfortunately this did partially inhibit some participants' ability to fully contribute their experiences due to various physical symptoms that restricted speech and strength. More information might have been received if all the participants had been less unwell but one criticism of palliative care research is that it mostly focuses on the less symptomatic patient population (Jubb 2002), hence this may also be a strength of this study.
- Age, Gender, Race: All the patients were older than the interviewer with an age gap of approximately five to thirty years (whereknown). Half the patients were male and half were female. Two participants were from the Caribbean. None of these factors appeared to have a discernable affect on the participants'



responses. The diversity of the patients hopefully counterbalanced any individual affect due to these factors

- **Role:** Not knowing is an important stance for the interviewer to take (Nunkoosing 2005). The patients were not aware of the researcher's experience in palliative care but were aware that she was a nurse. This may have contributed to the high levels of praise given to the nursing staff as Richards and Emslie (2000) found that participants were more complimentary about medical care to a researcher who was also a doctor. However some of the younger, less experienced nurses stated that they felt nervous being interviewed by someone they knew was a more experienced palliative care nurse. This may have inhibited some responses, despite efforts to reassure them about the benefits of different perspectives.
- **Locality:** One interview took place in a participant's home. This had a notably different atmosphere to the interviews within the hospice. Photographs of family members were discussed and the participant's spouse occasionally participated in the conversation. This emphasised the formality of the other interviews. Despite this, the data about the family history of disease did not appear to be significantly different in depth or content from the interviews that took place within the hospice.

Irrespective of where the interviews occurred, it is thought that that the high quality of care that the patients felt they had received from the participating hospice greatly contributed to the quality of the information received. It is thought that their openness about a complex and emotive phenomenon was based on the trust that they had in the participating institution.

### Hawthorne affect

The Hawthorne affect was described by Franke and Kaul (1978). It refers to the effect that being observed and studied has on research participants. Although its effect is considered to be a confounding factor in quantitative research, in qualitative research it is good practice to consider reflexively how the research has affected the views and perceptions of participants (Tod 2006). An effect was apparent in this study, especially with nurse-participants who had seen presentations about the research when the study was introduced to the participating hospice, helped recruit patients and cared for them after interview. This is illustrated by one extract which comes from one of the final interviews.

Researcher (I21): *Would you know where to go if you wanted further information for a family that was worried about a family history of cancer?*

Participant (NP9): *You know, I don't know that I would to be honest: I'd come to you.*

This awareness of the researcher's interest suggests that the nurse-participants had had the opportunity to think about some of the issues raised by the research study prior to the interview. This may have enriched the data as they had time to reflect on particular issues at length, giving depth to the information upon which the concepts generated from this study have been built.

### Analysis

The decision to view the data from an epistemological stance; in this case 'through a genetic lens', does not in and off itself give an interpretation validity nor does it make it invalid (Mason 2002). The rigour of the analysis comes from the power of inductive reasoning (Morton 2004), which ensures that the conclusions are connected to the evidence in a straight-forward way and that the conclusions do not go beyond the evidence given. This is a trustworthy method of reasoning (Morton 2004)

and it is hoped that the presentation of quotes, integrated into the text, provide adequate evidence for the analysis. For instance, it is reported in the theme '*Shadows in the mind?*' that many of the patient-participants did not think that their family history of cancer had affected their care needs. Nevertheless, it is hoped that the other quotes from the same patients, other patients and nurse-participants lend weight to the analysis of the multiple, subtle and complex effects that previous occurrences of cancer within the family can have on patients: even without the complications inherent in the issue of inherited susceptibility to disease.

Other steps that were taken to enhance the rigour of the analysis included triangulation, using negative evidence and exceptional cases as well as considering counterintuitive or initially implausible evidence carefully.

### Triangulation

Triangulation is the use of two or more data sources, theoretical perspectives or methods in a research study to compare findings and hence achieve greater validity (Gerrish and Lacey 2006). It allows the researcher to explore the research question from different perspectives (Mason 2002). This study had intended to triangulate three sources of data by interviewing patients, relatives and nurses with the aim of forming a more complete picture of the effect on families. The lack of relative-participants is a major weakness in this study. Nevertheless, reflection on Farmer et al (2006) triangulation protocol helped ensure that the analysis was credible and dependable. They suggest testing the data from different sets for agreement, partial agreement, silence and dissonance.

Agreement occurs when the meaning and prominence of a theme is the same within each data set (Farmer et al 2006). This occurred in the study; one example where

it enhanced validity was the confirmation that the nurse-participants gave to the exceptional case of Anne, who described her whole dying process as being dominated by an overwhelming distress related to previous deaths within her family. Although qualitative research is not about making generalisable findings based on sample size, one remains a very small number (Pyett 2003). Hence the fact that nurse-participants spontaneously mentioned similar rare scenarios was reassuring and added strength to the analysis (Farmer et al 2006).

Partial agreement occurs when both data sets agree on either the meaning or prominence of a theme but not both (Farmer et al 2006). This was common in this study. For instance, neither patients nor nurses had a clear concept of the inherited susceptibility to cancer. However, as discussed, it had strong emotional overtones for patients who did not know why they had developed their disease and expressed scepticism about all the medico-scientific explanations. In contrast, it had few emotional overtones for the nurses. Nevertheless they could, and did, give examples of how it affected the care of particular patients.

Farmer et al (2006) use the term 'silence' to denote the situation when one data set highlights themes that do not emerge in the other (Farmer et al 2006). As the nurse-participants were interviewed after much of the patients data had been coded it was possible to prompt them about some 'silences' in the data. For instance, prompts were added about the effect of multiple primaries and dying at a younger age than normal as no nurse-participant spontaneously mentioned these experiences. However, the full data analysis had not been completed. When this occurred it became evident that the patient data incorporated significant information about family coherence and communication that was missing from the nursing data set. More broadly, the nurse data was 'silent' about the role of the patient as an integrated member of their family whilst this was a

major theme for patients. These ‘silences’ have affected the structure of the analysis. This emphasised a benefit of accessing the patient’s perspective, they highlighted perspectives of their family history of cancer that were not apparent to nurse-participants.

Dissonance occurs when the different data sets disagree about both the meaning and prominence of themes (Farmer et al 2006). Remarkably there was no theme where the patient-participant and nurse-participant differed in both meaning and prominence. However triangulation did have one strength for this study which is rarely mentioned in the literature. It was ethically acceptable to ask nurse-participants openly and directly about their views on caring for people with an inherited predisposition to cancer in a palliative care setting. This is reported in the spatial analysis. It added a whole dimension to the analysis that did not emerge from the patient data, who only praised the hospice staff, and which could not be obtained by direct questioning of patients because of the sensitivity of the topic of inherited genetic disease.

### Counterintuitive Evidence

Counter-intuitive and/or puzzling findings can be extra-ordinarily rich and stimulating to data analysis (Miles and Huberman 1994). A prime example was the understanding gained about why the family history of cancer was rarely a focus of care outwith the genetics lens. This had not been considered at the start of the study but several participants (especially nurse-participants) made strong and unexpected statements about how the effects of a family history of cancer could be beneficial. This led to a re-examination of the data, leading to the emergence of themes ‘Shadows in the Mind?’ Further reflection on this theme, the lack of literature, alongside the lack of research into the effect of inherited disease eventually led to the concept of the missing

discourse as an overarching theme for this study. This in turn influenced the structure of the analysis, as using the missing discourse as an overarching theme enabled the analysis to consider the effect of the family history of cancer phenomena from both within and outwith the genetics paradigm.

### Negative Evidence

Looking for negative evidence ensures that none of the data contradicts preliminary conclusions (Miles and Hubermans 1994). Absence of negative evidence does not prove a conclusion but the presence of negative evidence can negate a working conclusion (Morton 2004). One significant example occurs in theme ‘No man is an island’. It was clear from the data that most participants associated the prospect of inherited susceptibility to disease with concern for their children, and that these concerns were present even in participants who did not necessarily associate their own illness with inherited cancer. However, Harry was a ‘negative example’ in that he was the only participant who had been told by an oncologist that his illness had a genetic aetiology but he did not associate this with any future concerns. This was instructive to the analysis. The absence of concern about the future of his family appeared to be linked to two separate reasons: firstly that he had no children and all bar one of his siblings had predeceased him or were living with cancer, although Jenny who also had no children expressed real and potent concern for her nieces. Secondly, it appeared to be linked to his scepticism about the scientific orthodoxy of the genetic origins of disease. This did not negate the other participants’ experiences or the finding that participants were dying with unresolved concerns for the future, rather it bounded the claims made from this study. It stopped the analysis from making a perhaps facile

assumption that the knowledge of inherited cancer was always associated with concerns for the future.

### Real World Validity

Pyett (2003) discusses the concept of real world validation and suggests it is important to pay attention to the real world validation (or invalidation) of research. She discusses how serendipitous external validation increased her confidence in her conceptual analysis. This has occurred on several occasions throughout the research process. For instance, a poster about the emerging findings was submitted to a postgraduate student poster competition, where a judge commented on how it resonated with her own family's experience. Similarly, a fellow student approached me after a presentation of my ongoing findings and offered to be a relative-participant. This was because the emerging findings resonated with their life experience and they wanted to support the study. Morse (2007) states that 'if you have developed your concepts well, they should be recognisable in other places, in other groups and in other situations' (Morse 2007: 148). This ongoing external validation of the study has been one of the most confirming aspects of the research process.

### **Conclusion**

Evidenced based care can be defined as the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients (Sackett et al 1996). The strengths and weaknesses of the research process have been discussed to facilitate the evaluation of the study's usefulness with regard to the care of palliative care patients who have a family history of cancer. Health care professionals have a duty to provide the best possible care to patients at the end of their lives (Hanks

et al 2005). It is anticipated that this study will help inform the care of patients who are concerned about their family history of cancer at a time when the clinical significance of genetic research into inherited predisposition to cancer is becoming increasingly important.



## POSTSCRIPT: REFLECTION ON THE PROCESS

*'The horror of that moment' the King went on, 'I shall never, never forget'.  
'You will though' the Queen said, 'if you don't make a memorandum of it'  
(Lewis Carroll: Through the Looking Glass: And what Alice saw there)*

### Through the Looking Glass

This research study had two main aims: the first frequently declared aim was to better understand how a family history of cancer affects the care needs of patients receiving palliative care. How well that aim has been achieved can be judged from the rest of the thesis. The second aim, which was implicit within the research process, was to develop my research skills. This has not always been the easiest of endeavours and at times I have felt like 'Alice through the Looking Glass' as I struggled to produce original and meaningful research.

.....

*'I don't quite know yet' said Alice very gently, 'I should like to look all around me first, if I might'. 'You may look in front of you, and on both sides if you like' said the sheep 'but you can't look all around you – unless you have got eyes in the back of your head'*

One of the most important lessons learnt through this process has been the contingent nature of research findings (whether qualitative or quantitative) and the need to be aware of (and wary of) the way research has been conducted to properly evaluate results. Whatever else has (or has not) been gained from the research process, I have become a much more critical consumer of research findings.

The extent that the epistemology and ontology of the research methodology influenced the research process has surprised me more than how the research process was affected by the practical 'real world' constraints of time, finance, ethics and opportunity. Rather to my surprise I found the philosophical basis of the research a satisfying and meaningful part of the process, and have endeavoured to be consistent

throughout the study. One key challenge, that I think was appropriately overcome, was the challenge of using the principles of phenomenology in a study where it was ethically inappropriate to ask the participants directly about aspects of the phenomenon under investigation.

I have frequently asked myself whether it was sensible to use a phenomenological method to study a phenomenon ‘the family history of cancer’ in a study where it was deemed (by me and others) as ethically inappropriate to ask about the phenomenon directly. As the study progressed I became increasingly aware of a second complication: that the phenomenon of a family history was conceived of very differently in different paradigms, and that the whole phenomenon was in the middle of a paradigm change. Most research proceeds within one paradigm (Kuhn 1996), and this is true for all the other nursing phenomenological studies I have encountered. The need to understand that the meanings and significance of the family history of cancer differed between participants who understood the aetiology of their disease differently, and that most participants juxtaposed insights and meanings derived from admixing aspects of paradigms (for instance, concerns for children’s future health were all given in the context of genetics, whilst no participant drew attention to genetic disease when discussing the previous deaths of family members who had died at a young age) was a complicating factor in this study.

Was it sensible to choose phenomenology for this study? I can only paraphrase Churchill on democracy: ‘Phenomenology was the worst choice of research methodology, except for all the other methodologies that have been tried from time to time’.

Managing the ethical issues that arose throughout the research process has also been exacting and stimulating. The need/desire to minimise the risk to participants

directly limited the scope of the study: most directly in the way it affected the recruitment of relatives. At the time I thought this was a catastrophe, as encounters with distressed relatives was one of the major triggers for this study, nevertheless with time, I have come to see it as a strength. It forced the study to focus on an aspect of the psychosocial impact of inherited multifactorial disease that has been a much neglected area of study (Hallowell et al 2004): the effect on patients.

.....

*'You don't know how to manage looking glass cakes' the Unicorn remarked, 'hand it round first and cut it up afterward'*

Kuhn's (1996) book 'The Structure of Scientific Revolutions' had a significant influence on the way that I analyzed the data obtained from this study. The concept of paradigm gave me a logically coherent, conceptual device with which to consider the data from two different perspectives. Kuhn uses the concept of a gestalt switch to illustrate how this occurs. There is, for instance, a well known drawing that can either be seen as a black vase on a white background or as two white faces looking at one another on a black background, (although both perceptions derive from the same real lines on a piece of paper). Kuhn (1996) states that a similar change of perception of the real world objects that are known through our senses occurs with a paradigm shift. This is because the relationships between different objects are considered differently, linked within a new framework and seen within a different lens.

This allowed me to not only look at the data about the family history of cancer and consider whether the topic was discussed by the participants from 'outwith' or 'within' a genetic lens, but also to take an interpretivist stance and consider the data that was given about the social and emotional consequences of a family history of cancer and link it together into a framework that was meaningful within the context of

an inherited genetic predisposition to cancer. Nevertheless I did feel like ‘Alice trying to manage looking glass cakes’ whilst doing this. It meant I had to pay close attention, not only to how the coded data related to interview data as a whole, but also to the lens through which I was coding the data. I have tried to ensure that this is sufficiently well signposted throughout the analysis for readers to be aware of the perspective taken.

I am, however, aware that this is a personal use of Kuhn’s concept of paradigm. Although the seminal nature of Kuhn’s work quickly led to it being a widely used concept especially in sociology (Bryant 1975), Kuhn primarily uses it with regard to the natural sciences.

.....

*‘I am real’ said Alice, and began to cry. You won’t make yourself a bit realer by crying’ Tweedledum remarked, ‘There is nothing to cry about’*

As discussed on p 42 I am a ‘realist’ in the sense that I believe that physical objects exist essentially independently from the mind of the perceiver. However, the epistemology that I adopted was social constructionism. This approach to knowledge is associated with ‘relativism’. Relativism asserts that in some sense what is true in one situation may not be true in another (Ruben 1991), and that truth is dependant on culture and experience (Ruben 1991). Hence it has been interesting to reflect on what is ‘real’ within this thesis and what is ‘relativist’.

What I understand to be ‘real’ is that real people, with real family histories of cancer, are dying with genuine concerns about whether their cancer might be due to an inherited genetic predisposition to disease. One concept that I have come to see as a relativist concept is the science of genetics. I now think of genetics (and the perception that cancer is a multifactorial disease), as a paradigm: a particular way of

understanding why some families have more cancer than others. The fact that I think that the genetics paradigm is useful (because of its potential to reduce the incidence of cancer in families with an inherited genetic predisposition, and because it allows individuals who are at increased risk of developing cancer to access health promoting measures) and a significantly better explanation of why some families have more cancer than other previous explanations does not mean that I think that it is the only way of conceiving of a family history of cancer. (For instance, I am very open to the potential for a new paradigm to emerge in the future that might explain the family history of cancer in a very different way). However the knowledge that my understanding that genetics is a relativist concept, because it is not independent of culture or experience does not prevent me from believing that it is having a real affect on people with cancer.

As I understand it, my ontological realism leaves me in an interesting position with regard to Heidegger. His seminal work, '*Being and Time*' (1927) is concerned with the ontological questions of 'being in the world'. I have, however, used a methodology (and taken an epistemological stance) that is based on his work (Krell 1991), without adopting his ontological stance. Perhaps surprisingly, this is not particularly unusual and is clearly discussed in the literature. Heideggerian phenomenology can be appropriately used as a methodology divorced from its philosophical roots (Farber 1991).

.....

*“I see nobody on the road” said Alice  
“I only wish I had such eyes” the king remarked in a fretful tone. “To be able to see  
nobody! And at such a distance too! Why it is as much as I can do to see real people by  
this light*

This thesis is called ‘The Missing Discourse’. This title reflects my bafflement at the lack of discussion about the effect of familial cancers on patients and family at the time of death. I found no information about this when I first looked to inform my practice. My best hope for this study is that it will provoke others to consider the issue more deeply and from different perspectives. It is too important a topic to leave to novice researchers. Pragmatically the lack of previous research has been both a blessing and a curse. It means that the research is truly original and gave me great freedom to look at the data and build my own analysis of the meaning and lived experience from scratch. On the other hand I found this process incredibly difficult.

I have felt like both Alice and the King in the quote above: at times wondering whether the whole issue was a chimera. Nevertheless I cannot see how a movement that professes that the *‘provision of psychological, social and spiritual support is paramount’* (NCPC 2007) can ignore it for much longer. The interblending of physical and social aspects of care is a novel challenge but, I think, one that needs to be taken seriously.

Nevertheless I found it incredibly difficult to delineate the subtle, complex processes described by the patients – who nearly all started by denying any discernable affect at all – before going on to tell their story. It was only through focused attention on the participant information that the insights into the phenomenon became apparent. I hope the analysis, which is as detailed as the word count allowed, persuades that this is a real phenomenon that will need to be taken increasingly seriously as the underlying mechanisms of inherited susceptibility to disease become better understood and more influential in treatment. I was, however, reassured by how much literature there was to

support the emergent themes and key findings. It was heartening to find that my findings juxtaposed nicely with other research that considered different but related discourses.

.....

*‘When I use a word’ Humpty Dumpty said in a rather scornful tone, ‘it means just what I choose it to mean – neither more nor less’. ‘The question is’ said Alice ‘whether you can make words mean so many things’. ‘The question is’ said Humpty Dumpty ‘which is to be the master – that’s all’*

The lack of prior research into the phenomenon has emphasised the need to be explicit about the fact that this is a hermeneutic interpretivist study. I undertook the research from a particular perspective, that I was nurse, interested in the nursing needs of patients. I have deliberately (and probably also sub-consciously) emphasised the aspects of the phenomenon that affect the nursing perspective. There is undoubtedly a powerful ability in taking a stance in research; nevertheless it does leave the research open to the potential for bias (Mason 2002). Chapter Eleven discusses the explicit steps that I took to minimise the bias and increase the trustworthiness of the investigation.

Although Humpty Dumpty’s words sound bleak, they in some ways echo Kuhn’s (1996) observation that science moves forward within a paradigm, and that how we perceive the world depends upon the paradigm in which we live. I think the paradigm of the multifactorial genetic/genomic aetiology of disease is an important paradigm and that palliative services will need, in time, to adapt to its consequences.

.....

*'Now here you can see it takes all the running you can do to keep in the same place. If you want to get somewhere else you must run at least twice as fast as that'*

Everybody warned me that undertaking research at this level is hard work, and it has been. Nevertheless there have been good moments. I really 'enjoyed' the interviews. The truth of the old adage 'Ask a different question and get a different answer' was stunning. It made me question the narrowness of some of my previous care. Transcribing was also eye-opening and made me re-evaluate my communication skills. Analysis, as stated, was tough, whilst writing has been revealing as seeing ideas in black and white has challenged me to think critically and more deeply. Writing and rewriting the study into an acceptable format has been the true '*horror*' in the process.

Completing a thesis is an individual endeavour but doing research is not. I want to end by again thanking all the participants who made this study possible. They did so primarily to help elucidate the meaning of a family history within palliative care: but in so doing they also helped me develop my research skills. This makes my debt to them personal as well as professional.



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## APPENDICES

### Appendix 1: The Amsterdam Criteria and the West Midland Family Cancer

#### Service Guidelines (WMFCS) for referral

### The Amsterdam Criteria

The following clinical criteria were established in 1991 to facilitate consistency in research. The criteria are now applied in diagnosing Hereditary Non-Polyposis Colorectal Cancer (HNPCC):

- **3 or more cases of colorectal cancer**
- **in a minimum of 2 generations**
- **1 affected individual should be first-degree to the other cases of colorectal cancer**
- **1 case of colorectal cancer should be diagnosed under age 50**
- **A diagnosis of Familial Adenomatous Polyposis (FAP) should be excluded**

The criteria have since been modified - summary below:

- **2 cases of colorectal cancer where families are small (one age under 55)**
- **2 cases of colorectal cancer and 1 case of endometrial cancer, or other early onset cancer**

## **WMFACS cancer family history referral guidelines**

Many individuals have concerns about a family history of cancer. However, less than 10% of all cancer is due to an inherited predisposition. Even in those rare families where this is the case, unaffected family members have a greater than 50% chance that they will not develop an inherited cancer. It is unlikely that familial cancer clusters are inherited if:

- Different cancer sites are involved
- The cancers occur later in life
- The cancers have a strong environmental influence such as smoking or U.V. light

### **Breast Cancer**

- 1 close relative, age under 40
- 1 close relative with bilateral disease
- 1 male relative, any age
- 2 close relatives, age under 60
- 3 close relatives, any age

### **Ovarian Cancer**

- 2 close relatives with ovarian cancer, any age

### **Breast AND Ovarian Cancer**

Minimum of 1 of each tumour; ovarian cancer any age, breast cancer age under 60

### **Colorectal Cancer (or Colorectal Polyps)**

- 1 close relative age under 45
- 2 close relatives, average age under 70 (includes both parents)
- 3 or more close relatives, or with other gastrointestinal, renal, urinary tract, uterine or ovarian cancer at any age
- Familial Adenomatous Polyposis (FAP)

## **Other cancers**

- Multiple primary cancers in one individual
- 3 or more relatives with cancers at the same site
- 3 or more relatives with any cancer at an earlier age than expected in the general population
- 3 or more relatives with cancers of breast/ovary/prostate/pancreas/melanoma/thyroid, or other non-melanoma skin tumours or carcinoma

**The overall benefit of surveillance outside these guidelines has not been established**

Close relatives are:

- mother/father
- sister/brother
- son/daughter
- aunt/uncle
- grandmother/grandfather

Please make sure that you have considered recognised associated familial cancers when applying the guidelines.

**If uncertain, please refer for assessment.**



## **Appendix 2: Eugenics and the 'New' Genetics**

Although a discussion of eugenics, biological determinism and discrimination may not seem directly relevant to the context of this research, the study was carried out whilst the Human Fertilisation and Embryology Authority was discussing an application to screen embryos for a genetic predisposition to breast and bowel cancers (in families where it was thought that an affected embryo had an eighty per cent lifetime risk of developing cancer). This received widespread media coverage (for instance, [timesonline.co.uk](http://timesonline.co.uk) 01/11/2004, [news.bbc.co.uk](http://news.bbc.co.uk) 08/05/2006), whilst the interviews were proceeding. Hence debate about whether society should allow individual families the choice of having a child without an inherited predisposition to cancer was a topical issue during the research process.

Concerns about selective reproduction are closely linked with the history of the eugenics movement. This culminated in the well-documented link between eugenics and the Nazi ideology with forced abortion, sterilisation and murder committed in the name of racial purity (Ridley 1999, Jones 2000). The roots of the concept of social discrimination based on biology can be traced to Hobbes (1588-1674). Hobbes considered that human behaviour was based in human biology. His understanding incorporated two philosophical components that are still important in current debates: reductionism and biological determinism (Pilnick 2002)

Reductionism is the attempt to explain the properties of complex systems and objects in terms of the basic units that make up the systems or objects (Pilnick 2002). Biological determinism can be viewed as a particular case of reductionism. It considers that human lives and actions are the consequences of the biological properties of the cells that make up an individual (Rose et al 1984). Hence a biological determinist would suggest that genes govern the properties of cells, which in turn govern the

characteristics of individuals, which then govern the characteristics of society (Pilnick 2002).

Hence the eugenics movement did not see social inequalities arising due to cultural or social factors, rather as expressions of biological meritocracy (Pilnick 2002).

Initially, eugenicists like Galton (1822-1911) focused on encouraging the interbreeding of the best human stock to improve the human race. However in many countries biology became enmeshed with nationalism. This produced a drive for evolutionary progress to be combined with economic progress (Ridley 1999). At the same time the focus of eugenics shifted to discouraging dysgenic breeding. This was endorsed by the legalised, state enforced sterilisation of people with learning difficulties and the mentally ill in many countries including the USA, Sweden, Canada, Norway and Germany (Ridley 1999).

There was a rise in the support for psychological and sociological explanation for human behaviour after the Second World War leading to enthusiasm for social and environmental schemes to improve the human condition (Cunningham-Burley & Kerr 1999). There was also an increased awareness of the role of human agency in realising desired futures (Bandura 1997). However recent research into genetics and molecular biology has led to genetic determinism being in vogue once more (Cunningham-Burley & Kerr 1999). There have, however, been deliberate and specific strategies to limit the association of the 'new genetics' with historical eugenics movement (Cunningham-Burley & Kerr 2002). This is achieved by focusing on the rights of individuals rather than the good of society, and by emphasising voluntary action rather than coercive practice. However, it can be argued that appeals to individual choice do not take serious account of the social context within which choices are made (Cunningham-Burley & Kerr 2002). For instance, the promotion of health as a right and value can be perceived

as constraining choice as choosing to have a child with a genetic predisposition to disease might be deemed irresponsible (Shakespeare 1999, Cunningham-Burley & Kerr 2002). In other instances society has deliberately chosen to restrict choice: for instance, by refusing access to information about the sex of a child to prevent parents selecting the gender of their children (Pilnick 2002).

Pilnick (2002) suggests that the real conflict between biological determinism and human genetics is the concept of potentiality. That is that molecular biology can only tell us about the genetic possibility for people to develop or acquire certain traits or diseases in certain contexts and environments and that, with rare exceptions, there is not a simple division between nature and nurture. Consequently, except in certain genetic illnesses that have a high penetrance, it is now recognised that the social, physical, environment and lifestyles factors play a significant role in determining diseases (Petersen 2006) and that there is a huge complexity in the genotype-phenotype relationship (Cunningham-Burley & Kerr 2002). Consequently, reducing individuals to their genes does not allow them to be fully understood until we fully understand the interactions between genes and the environment as well as the interactions between individuals and society (Pilnick 2002).

There are many other concerns and discussions about the social consequences of the rapidly expanding understanding of human genetics (Cunningham-Burley & Kerr 1999, Conrad & Gabe 1999, Cunningham-Burley & Kerr 2002, Bunyon & Peterson 2005). Many of these focus on practical concerns about the use and misuse of genetic information. This is because genetic information contains both a unique identifier of every individual, as well as heritable information that has relevance to other family members (Feetham & Thomson 2006). Important concerns include issues of confidentiality, choice and discrimination. Sadly, society has a history of prejudice

about issues that are associated with genetic inheritance like race, colour, gender and disability. Harris & Sulston (2004), therefore, suggest that a principle of genetic equity consistent with other human rights should be established. They state

‘We propose the following principle of genetic equity: humans are born equal; they are entitled to freedom from discrimination and to equality of opportunity to flourish; genetic information may not be used to limit that equality. It follows that neither genetic constitution nor genetic information should be the basis of discrimination or stigmatisation of an individual, family or group. No individual’s genes, or genetic information about them, can or should detract from their equal standing and dignity in the community and their equal entitlement to the concern, respect and protection of others or of society’ (Harris & Sulston 2004: 798)

### **Appendix 3: Recruitment of Relatives**

As stated, in the first iteration of this study it was intended that both patients and relatives (first degree blood kin) would be recruited into the study. Ethical approval for this was both sought and given. However, the local research ethics committee specifically stated that the patients' consent was required prior to inviting their relatives to participate in the study (even if the patient to whom the relative was related was not themselves participating in the study). This led to a new exclusion criterion being added to the study protocol; that no relatives would be included as participants if the patient to whom they are related objects to their participation. This criterion had a significant effect on relative recruitment.

No relatives were recruited into the study. This was a major concern whilst data collection was being undertaken. Considerable thought was given to trying to understand why the researcher was able to recruit patients into the study but not relatives, with the aim of facilitating the recruitment of relatives.

One key factor appeared to be gatekeeping. This has been defined as 'the process by which people's capacity to be invited into a research project, or to make an informed decision regarding research participation, is inhibited by others' (Hudson et al, 2005: 165). This can occur at three levels: institutional, professional and family. The key factor preventing the recruitment of relatives in this study was the patients' desire to protect their relatives. For instance, nine of the twelve patients were asked if their relatives could be approached to participate in the study. All refused. The most commonly given reason was that their illness was already greatly burdening their next of kin and they did not wish to add to this in any way. In some instances this sense of burden was expressed in terms of physical workload

*'Since I've been given the one-way ticket upwards, all the pressure has gone on to her because she does all the forms and everything. She does all the cooking;*

*she does all the runs to the hospitals and everything. I know it is doing her head in ... She won't let me do nothing for her (Iain)*

Other patients were more conscious of the emotional burden that their illness was putting on their relatives

*My husband says that he doesn't think he can live without me ... that he can't imagine not having me in his life (Grace)*

Other reasons included family discord and not wanting their relatives to talk about them. No patient-participant explicitly mentioned the sensitivity of the research topic or fears that the interview might make their relatives re-evaluate their family history of cancer; however it remains possible that this was an undisclosed cause for concern. Gatekeeping by patients is the most difficult type of gatekeeping to challenge within palliative care research and it is recommended that researchers who are denied access to family members respect this (Hudson et al 2005).

Attempts to recruit relatives who were not related to patient-participants continued for six months after the decision to stop recruiting patients was taken. This was unsuccessful. It has been suggested that using external clinical staff to recruit participants can lead to inappropriate or excessive gatekeeping (Hudson et al 2005). However Ross and Cornbleet (2003), who studied the attitudes of staff and patients to research studies in a hospice setting, found little evidence of this, saying that the culture of research has become more prominent in palliative care units (Ross and Cornbleet 2003). Similarly, in this study the clinical staff did not appear to be unnecessarily gatekeeping participants (as demonstrated by the recruitment of patients into the study); rather the process of relative recruitment appeared to be too complex. Firstly the hospice link staff did not always know the relatives as well as they knew the patients. For instance, one nurse stated

*The whole relative thing is where I think I am getting a bit unstuck because I'm aware that we don't always meet the relatives ... We don't get involved in the same way (Link Nurse)*

Secondly the relatives had to be approached in two stages. Initially the patient had to be informed of the study by the hospice link nurse to gain their permission to discuss the study with their relatives as stipulated by the ethics committee. Then the relative had to be approached and informed of the study separately. This meant that the link staff had to consider whether both the patient and their relatives were able to give informed consent to the study. Ross and Cornbleet (2003) found that around fifty percent of hospice in-patients were inappropriate for recruitment into any research study due to confusion, frailty and impending death. The researcher was aware that some relatives were not invited to participate because the link staff did not think that the patient to whom they were related were capable of consenting/or would consent to their relatives' involvement. Similarly, it is known that a small number of relatives were approached to participate in this study with the patients' permission but that they refused.

Ideas for simplifying the process of relative recruitment were considered. However as the requirement to obtain the patient's permission to recruit relatives into the study had originated with the ethics committee it was not thought appropriate to challenge this. Other ways of increasing awareness of the study were discussed: for instance, the possibility of placing posters about the research in the visitors' room. This might have increased awareness of the study amongst potential relatives and patients making it easier to initiate discussion about the research. However the participating hospice did not want display research posters in public areas so the idea was not taken back to the local research ethics committee. After ten months of trying to recruit relative-participants it was decided to desist and to refocus the research study entirely on the patient experience as presented in the thesis.

## Appendix 4: Interview Proforma for Patients

This proforma indicates the anticipated structure of the interview with patients.

### A) Opening question

1. Can you tell me about yourself and your experience of cancer?

*Probe*

### B) Questions about the participants understanding of cancer?

- : understanding of their own cancer*
- : causes of cancer*
- : where have they learnt about cancer*
- : do they discuss with other members of the family*

### C) Questions about previous experiences of cancer within the family

- : About family without cancer*
- : About how this has affected their own experience of cancer*

### D) Questions about Care Needs of Participant in the hospice

- : about how the previous experiences within the family have affected their care needs*
- : about how their understanding of cancer has affected their care needs*
- : about any specific incidences, people or actions that they feel have been particularly helpful to them in their care re above*

### E) Questions about perceived family understanding and care needs

- : whether they are able to discuss their experience with family*
- : whether they have discussed their understanding with the family*
- : whether they think family would know where to go for information*

### F) Final Questions

1. Is there anything else about the way the previous experience of cancer in your family has affected your understanding; Is there anything which I have not mentioned, which you think is significant?

2. Do you have any questions for me?



## Appendix 5: Interview Proforma for Nurses

This proforma indicates the anticipated structure of interviews with healthcare professionals

### A) Opening question

1. Can you tell me about a memorable scenario (past or present), in which you were involved, where a previous experience of cancer had a significant affect on the care needs of a patient and their family

-: *Why was it memorable? What made it distinctive?*

-: *What did you learn from it?*

### B) Questions about how information about family history obtained by participant.

1. Do you routinely discuss a family history of cancer with patients and their family?

*Probe: When? Why? How?*

1b. (If answer to Q1 is no) When would you discuss previous experience of cancer with patients and their family?

*Probe: Why?*

2. How do you feel about discussing previous experiences of cancer within the family with patients and relatives?

*Probe: What reasons?*

*Probe: Is it similar or different with relatives?*

### C) Questions about understanding of cancer

1. What do you think causes cancer?

2. What do you think causes a family history of cancer?

*Probe: Understanding of difference between inherited and familial cancer*

### D) Questions about perception of care needs when there is a family history of cancer

1. How do the think that the cause of cancer makes a difference to the care needs of patients and their families receiving palliative care?

*Probe:*

2. How do you think a previous experience of cancer within a family usually influences the care needs of patients and their families receiving palliative care?

*Probe: Affect on patient experience/ Staff experience*

*Probe: Positive and Negative affects of experience*

3. Can you tell me about a time when you, or a patient, raised the topic of health promotion (eg smoking, diet, exercise) in a scenario where you, or the patient, felt shared risk factors might be a part of a family history of cancer

*Probe:*

4. Can you tell me about a time when you, or a patient, raised the topic of genetic counselling when you, or the patient, thought genetic mutation might be part of a family history of cancer?

*Probe*

5. Where would you go if you wanted further information or support for a family who was worried about a family history of cancer?

*Probe*

#### E) Questions about the future of care of the family in palliative care

1) How do you think that an increased awareness of the genetic linkage of some cancers will affect the care of the family in palliative care in future?

*Probe about children/ grandchildren, same generation and older relatives?*

*Probe about patient care also?*

2) Have you ever cared for a family with a known genetic mutation for cancer?

2b) If not, have you considered what you would do in it did occur and what do you think that the major issues will be?

*Probe*

3) Do you think that a palliative care setting is the right place to consider the implications of a family history of cancer?

*Probe: If no, where do they think is the appropriate place*

*Probe: if no, why not*

*Probe: if yes, what reasons,*

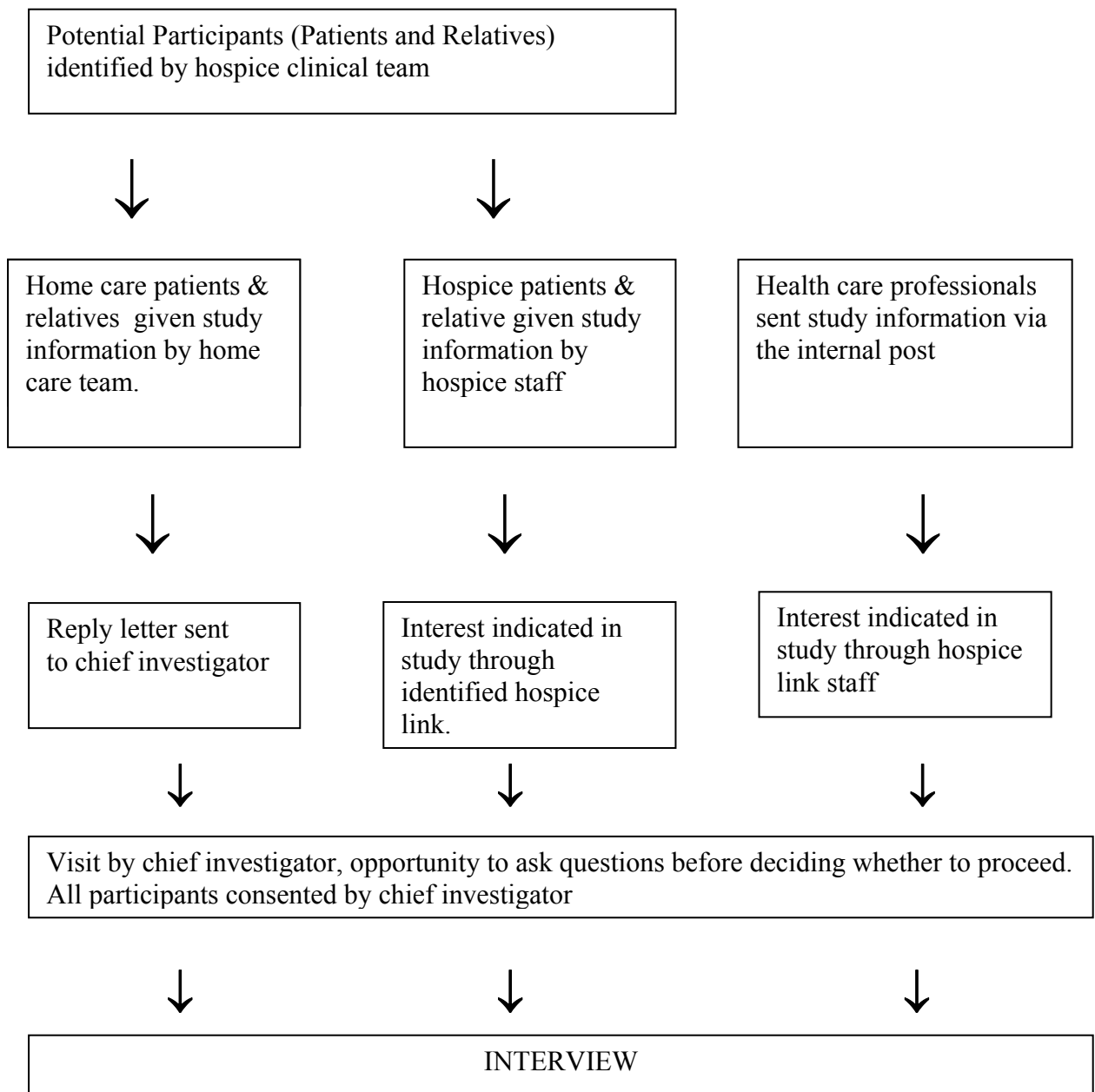
*Probe: if yes, transferable skills*

#### F) Any Questions

1. Is there anything else about how a previous experience of cancer within a family affects the care needs of patients and their families within the hospice, which I have not asked yet, which you think would be relevant to this study?

2. Do you have questions for me?

## Appendix 6: Recruitment Flowchart



## **Appendix 7: Introductory Letter**

Hello

My name is Kate Lillie. My background is in nursing and I have an ongoing interest in hospice care. I am now working as a research and teaching assistant in the School of Health Sciences at the University of Birmingham.

In my work, as a researcher, I am looking at how the understanding of cancer, and previous experience of cancer within a family, affects care needs of patients and their relatives receiving hospice care. I am inviting patients, healthcare professionals and relatives of patients receiving care from the (*Hospice Named*) to be interviewed for this study.

Please read the information sheet, which is enclosed with this letter, to see what this involves. If you are interested in taking part, please inform (Named hospice link). I will arrange to visit you to answer any further questions that you have and see if you wish to take part in the study.

Thank you for your consideration of this study

Yours Faithfully

## **Appendix 8: Information Sheet**

### **An invitation to take part in an interview for a research study**

You are being invited to participate in a research study. Before you decide whether or not you wish to take part in this study it is important that you understand why the research is being done and what is involved. Please read this information carefully and discuss it with friends, relatives and health care professionals if you wish. If there is anything that is not clear, or if you want more information about the study, please ask. I can be contacted using the details given at the top of the page. Please take time to decide whether or not you wish to take part.

**Full Name of Study:** Family care and cancer in a hospice setting

### **What is the purpose of this study?**

There is at present very little information about how a previous experience of cancer within a family affects the care required by patients and their relatives in a hospice setting. In this study I will be talking to patients, relatives and health care professionals working at (Hospice Named), to find out their views on this subject.

### **Why have I been invited to take part?**

You have been invited to take part as you may have indicated to the hospice that another member of your family has had cancer in the past. I wish to interview up to twelve patients and twelve relatives of hospice patients to find out how they think their previous experiences of cancer affects the care needs of patients and their families receiving hospice care. You may take part in this study if you are a relative of a patient receiving care at (Hospice named) even if the patient to whom you are related does not wish to participate.

I will also be talking to doctors and nurses about this.

### **Do I have to take part?**

NO, it is up to you to decide. If you do decide to take part, you are still free to stop at anytime and you do not need to give a reason. It will not affect your usual care if you decide not to take part.

### **What will happen if I take part?**

I will arrange to come and interview you. During the interview I will be asking questions about

- Your own experience and understanding of cancer
- How you feel that previous experience of cancer in your family has affected your own experience and understanding of cancer
- How you think that this affects the care that you and your family need from the hospice now

The interview is expected to take around one hour. With your permission the interview will be recorded. I will be the only person who will have access to the recording. The tape will be destroyed as soon as the interview is written up.

**What are the possible risks of taking part?**

As health problems associated with cancer do cause distress there is a risk that you may become upset during the interview. You or the researcher may choose to stop if this occurs.

**What are the possible advantages of taking part?**

You may find it interesting to talk about your own experience and understanding of cancer and how you think it has been influenced by previous experiences in your family. However the researcher is not a counsellor and the interview may not be beneficial to you. It is hoped that information from this study will help hospices understand how best to support other patients and families in a similar situation to your own in the future.

**Will my part in this study be kept confidential?**

Yes, all the research information is strictly confidential. All names will be changed when the research is written up. Some hospice staff may know that you participated in the study but they will not know about what is said during the interview. The tape recording of your interview will be kept in a locked cupboard and then destroyed when the interview has been written up. The transcription will not have your name or address on it. I will use a study identification number. I do not have access to your hospice notes or any other confidential information held by the hospice about you.

**Who has reviewed this study?**

The South Birmingham local research ethics committee has reviewed this study. They aim to ensure that it is very unlikely that research will harm anybody.

**What will happen to the results of this study?**

It is intended to publish the results in a nursing or palliative care journal as well as presenting them to the hospice. The researcher also intends to write up the results in a format appropriate for the award of a PhD at the University of Birmingham.

**Who can I contact for further information?**

Please do not hesitate to contact me if you want further information about this study. My name is Kate Lillie and I am the researcher for this study. The contact details are at the top of the first page or you can ask the hospice nurse who gave you this information to contact me on your behalf.

**What if something goes wrong?**

This study is being sponsored and funded by the School of Health Sciences at the University of Birmingham. If you have any complaints about this research: how it is being conducted, or how you have been treated, you should contact the research administrator, [name, contact details]

**Thank you for reading this**

## Appendix 9: Reply Letter

**Research Title:** Family care and cancer in a hospice setting

Dear Kate Lillie

I have read the participant information sheet about the study “**Family care and cancer in a hospice setting**”. I am interested in the study and am willing for you (Kate Lillie) to have my contact details as written below. I realize that this does not commit me to taking part in this study but will allow you (Kate Lillie) to contact me so that I can ask further questions prior to deciding whether I wish to be interviewed for this study.

Name: .....

Address.....

.....  
.....  
.....  
.....

Telephone.....

Email (if appropriate).....

## **Appendix 10: Letter to Hospice Link Staff**

Dear 'Hospice Link Nurse'

Thank you for agreeing to act as a link member of staff between the hospice and myself for the research study 'Family care and cancer in a hospice setting'

As we discussed the main elements of this role is to help with the identification of appropriate patients and relatives who are physically, mentally and emotionally fit for interview and are able to give informed consent. It also involves giving potential participants the research information sheet and liaising with me about potential participants.

As you know, there is the potential for concern about the ethics of combining the role of a health care professional with involvement in research. One reason is that patients can feel obliged to participate, either because they want to please the people who provide care for them, or as a way of saying 'thank-you' for the care they have received. This can be particularly true in a hospice environment where the social, emotional and spiritual aspects of cancer may have been addressed for the first time. Hence I am asking you to ensure that any potential participant you approach is aware that I am working for The University of Birmingham and am not part of the care team at the hospice. It is very important that no patient is pressurized to participate in this study and that they know that their care will not be affected in anyway if they decide not to participate.

Once again thank you for your willingness to act as a link person for this research project. Please do not hesitate to contact me at any time if you have any further questions about this or any other aspect of the study

Yours sincerely

Kate Lillie



## Appendix 11: Consent Form

Title of Study: Family care and cancer in a hospice setting

Name of Researcher: Ms Kate Lillie

Please tick the box

1/ I have read and understood the participant information sheets and have had a chance to ask questions.	Yes <input type="checkbox"/> No <input type="checkbox"/>
2/ I understand that my participation is voluntary, and that I am free to withdraw at any time, and that this will not affect my medical or nursing care or my legal rights.	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
3/ I give permission for the researcher to inform ( <i>Hospice named</i> ) that I am taking part in this study	Yes <input type="checkbox"/> No <input type="checkbox"/>
4/ I understand that the interview will be taped and that the recording will be destroyed when the transcription is completed	Yes <input type="checkbox"/> No <input type="checkbox"/>
5/ I agree to take part in this study	

Name of Participant.....

Signature.....

Date.....

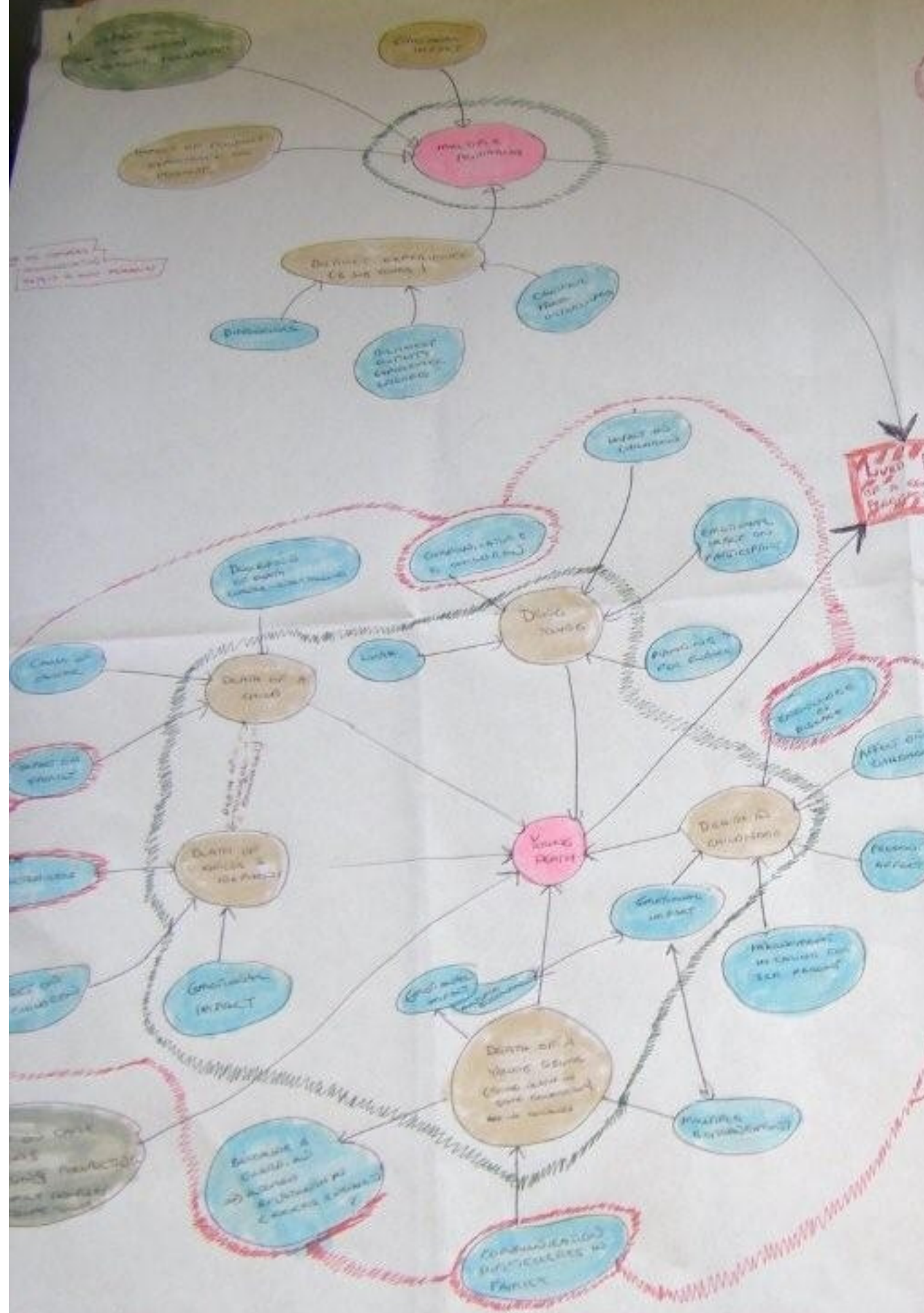
Name of Researcher.....

Signature.....

Date.....

## **Appendix 12: Matrix for Data Analysis**







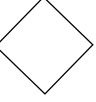





(see over page)



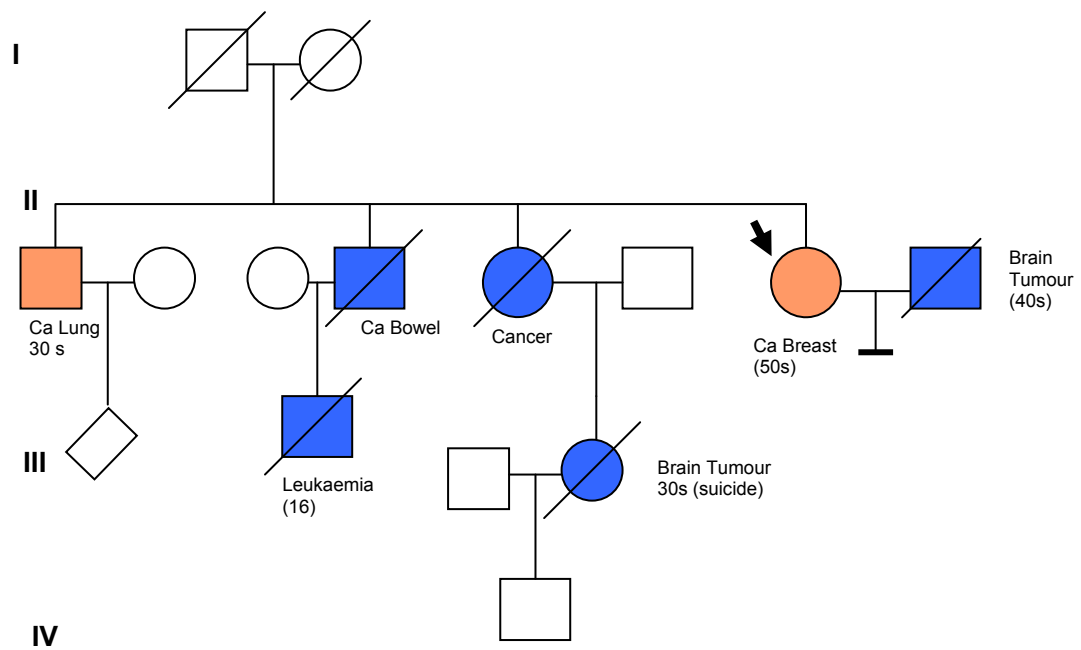
**Appendix 13: Family Trees**

**Appendix 15**

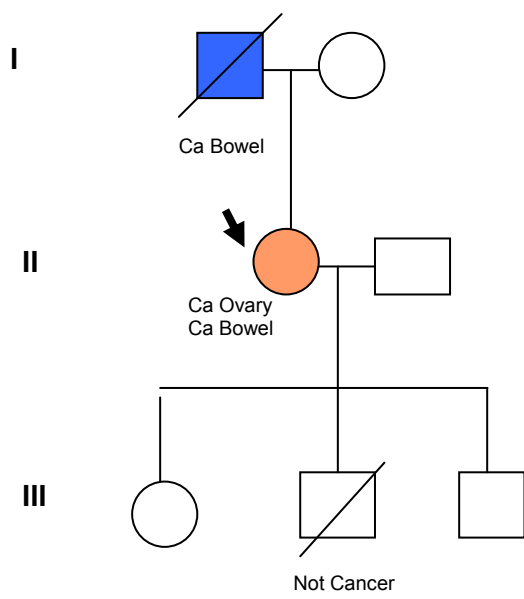
**Key For Family Trees**

	Participant		Deceased
	Female		Died from Cancer
	Male		Living with Cancer
	Sex Unknown		Cancer discussed as possible Cause of death
	Multiple Individuals Numbers Known		Adopted/ Became legal guardian
	Multiple Individuals Numbers Unknown		No Children Reason Unknown

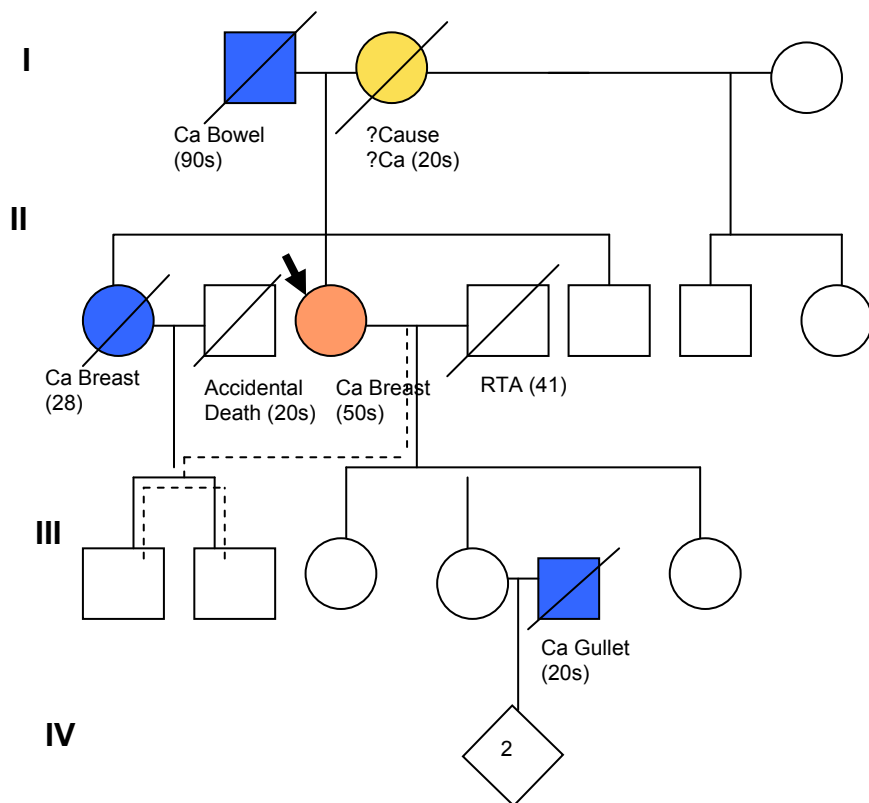
NB: For the reasons discussed on p 76 these family trees are incomplete and probably contain inaccuracies



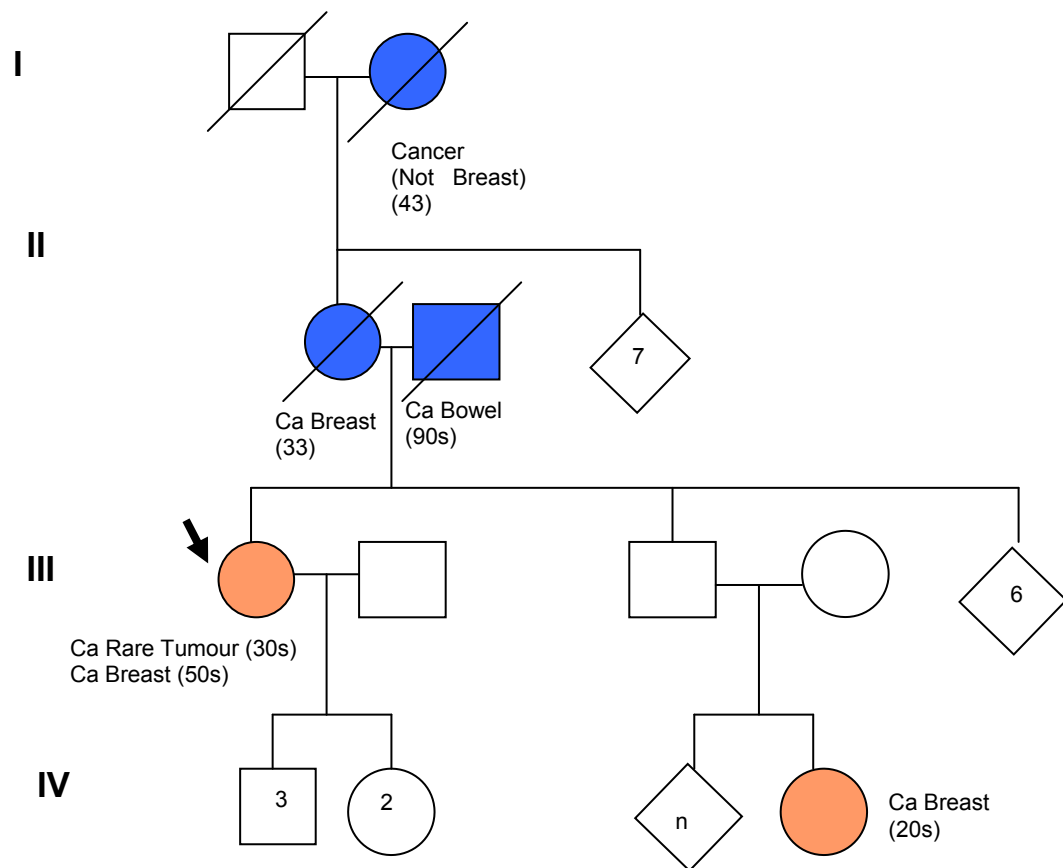
**Anne's Family Tree**



**Beth's Family Tree**

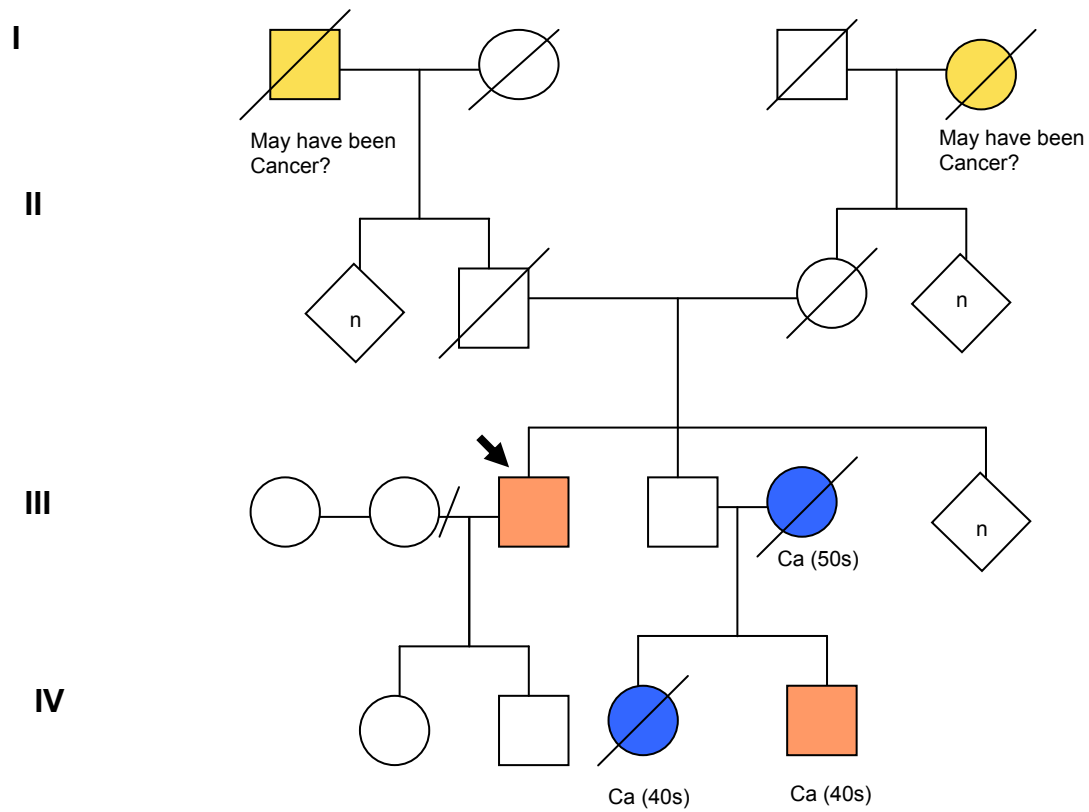


**Claire's Family Tree**

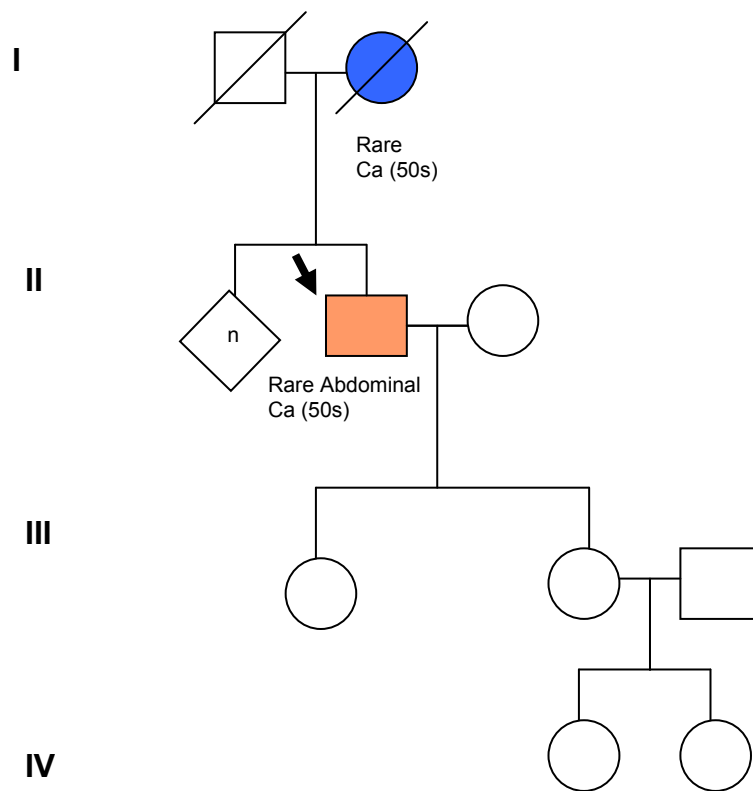


**Diane's Family Tree**

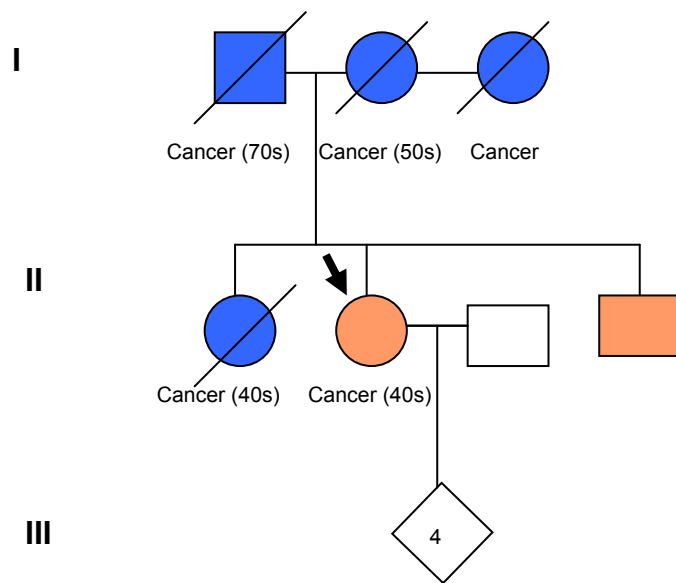




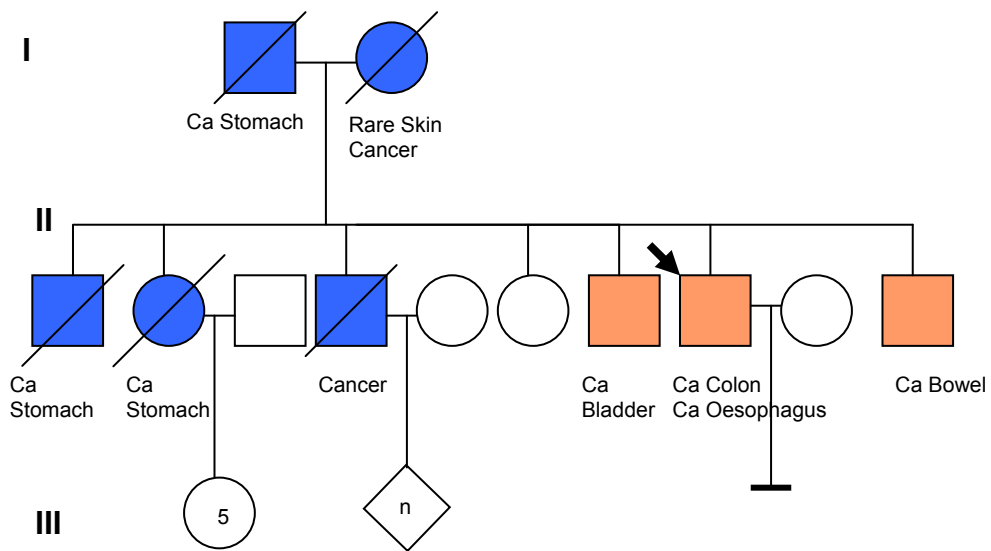
**Ezra's Family Tree**



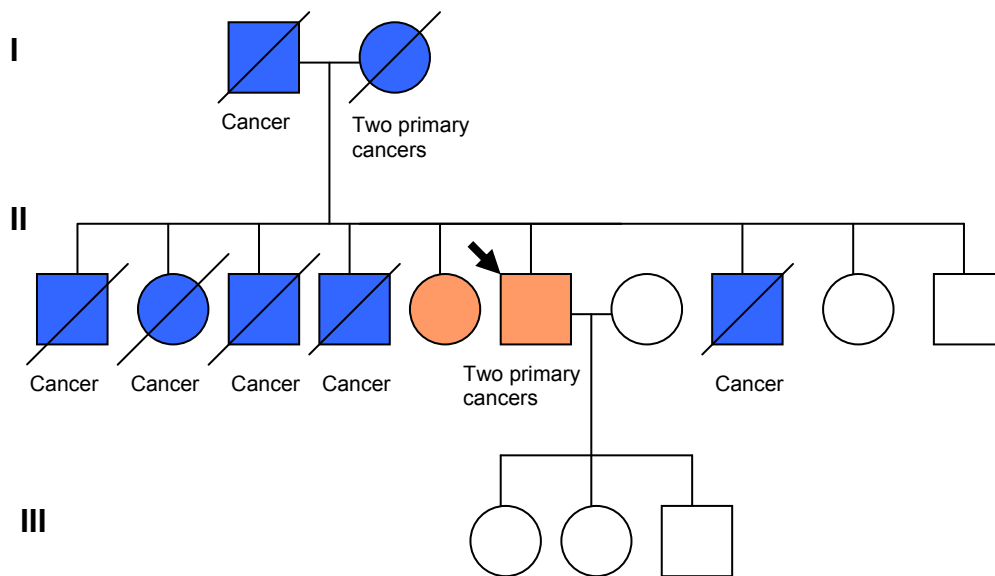
**Finlay's Family Tree**



**Grace's Family Tree**

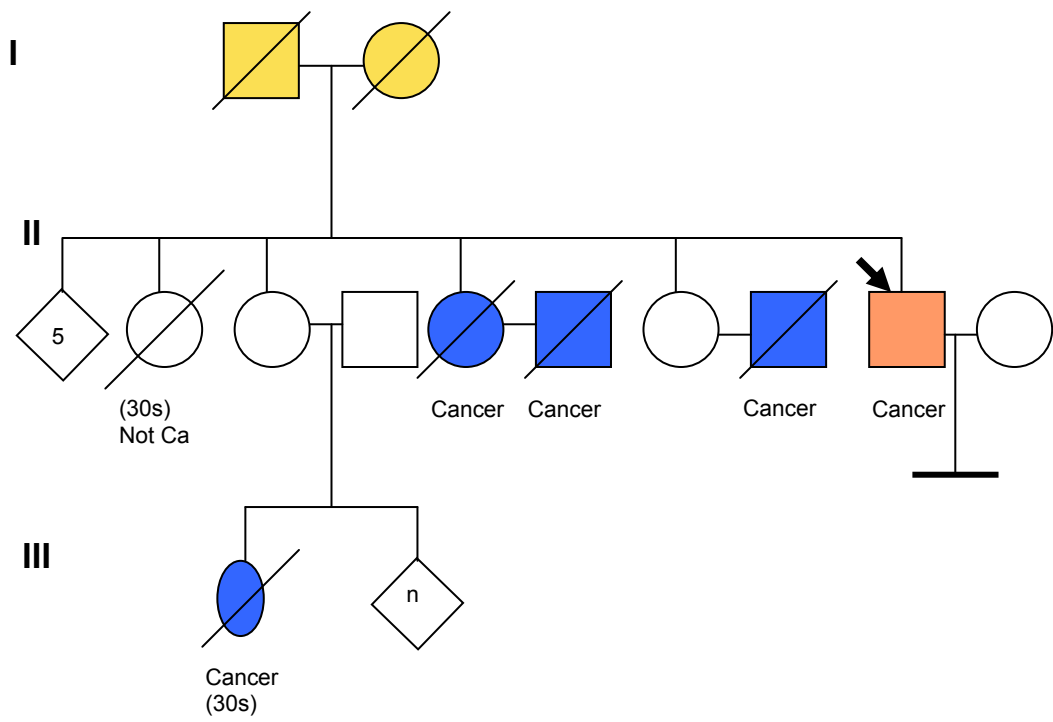


**Harry's Family Tree**

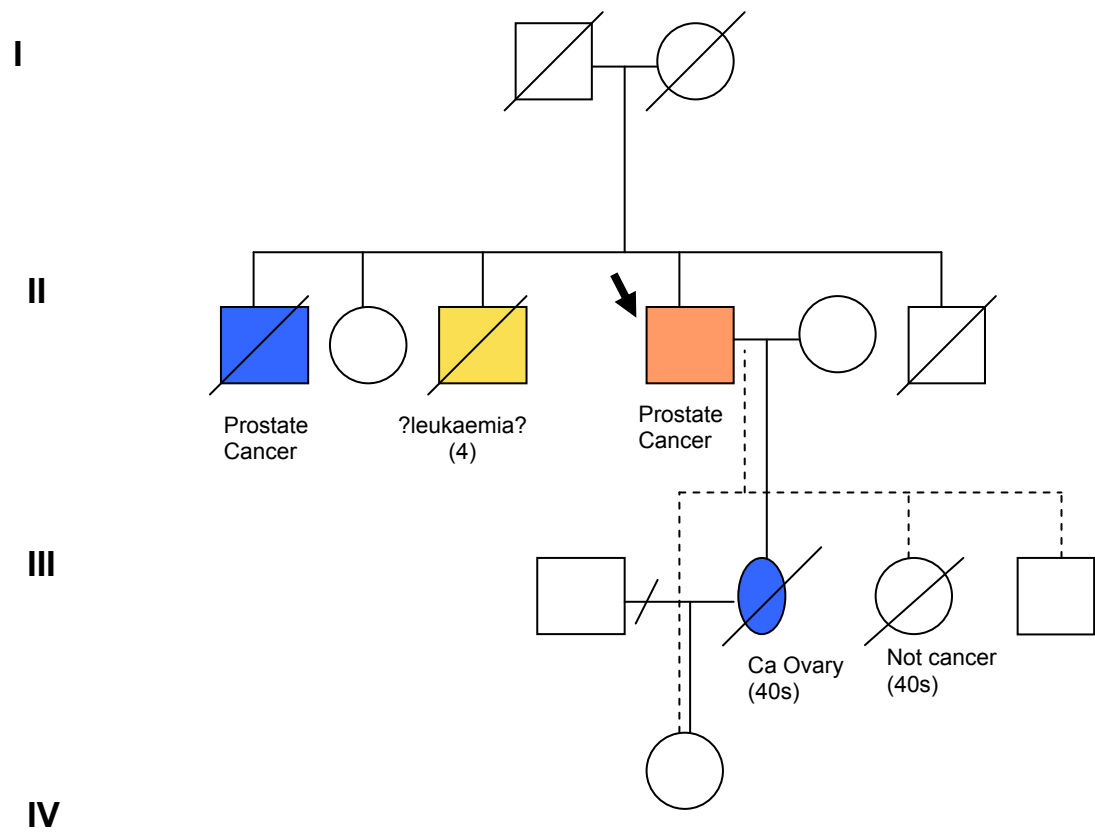


**Iain's Family Tree**





**Keith's Family Tree**



**Leon's Family Tree**



## **Appendix 14: Papers and presentations arising from this study**

### Papers

Lillie, A.K. (2006) Exploring cancer genetics and care of the family: an evolving challenge for palliative care *International Journal of Palliative Nursing* 12(2): 70-74

### Conference Presentations and Posters

Lillie, A.K. (2008) Dying with a family history of cancer: A phenomenological study European Meeting on Psychosocial Aspects of Genetics Barcelona, Spain 31/5/08-3/6/08 (European Journal of Human Genetics 16, Supplement 2: 462)

Lillie, A.K. (2008) End-of-life care required by patients and families affected by an inherited genetic cancer: In Symposium 9: Building a programme of genetic research to inform practice: Metcalfe, A, Coad, J. Lillie, A.K. Royse, S. *RCN International Nursing Research Conference* Liverpool 8-11 April 2008: (RCN Events Book of Abstracts: 117)

Lillie, A.K. (2007) How does a family history of cancer affect the care needs of palliative care patients? *The Social Context of Death, Dying and Disposal: 8<sup>th</sup> International Conference* 12-15 September 2007: Bath UK. (Mortality 12 Supplement: 56)

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